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Improving faecal continence among care home residents living with dementia: developing an intervention and conducting a feasibility study

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A thesis submitted in partial fulfilment of the University's requirement for the Degree of Doctor of Philosophy

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ABSTRACT

Background: Faecal incontinence is an under-reported but debilitating health problem that affects people of all ages, and particularly older people aged 65 years and above living in care homes, many of whom have comorbidity such as dementia. Prevalence of faecal incontinence is high in the group, but the exact prevalence is unclear. Faecal incontinence can have significant negative impact, including low self-esteem, feeling stigmatised (and leading to social isolation), and sometimes death. In older people, faecal incontinence is not only the consequence of age-related anorectal deficits such as reduced anal sphincter pressure, but also cognitive decline, care home placement, diarrhoea, constipation and/or effects of polypharmacy. However, faecal incontinence remains a taboo subject because people with the condition are too embarrassed to discuss their symptoms with their family or health care workers. Health care workers, on the other hand, do not routinely broach the topic with patients perhaps because of therapeutic nihilistic attitudes (the belief that nothing can be done to help). In a care home, where most residents live with dementia, this nihilism can mean that residents are not assessed to find out why they are incontinent, thus resulting in the routine use of incontinence pads by care staff. Within the care homes, intimate care such as continence care, bathing and dressing of residents is mostly carried out by care assistants (and occasionally by registered nurses). The care home managers often avoid these messier dirty works because care work for the older people involve bodily dysfunctions and discharges such as blood, vomit, urine, faeces, illness, and death. Therefore, the emotional labour of the care homes' care workers is an important skill that has therapeutic value to both the care staff and the residents experiencing faecal incontinence. The development of a theory-driven, context-dependent intervention to manage FI is needed for this population.

Methods: The overall aim of this thesis was to develop a context-dependent, complex intervention for the management of faecal incontinence in people living with dementia in care homes and test it for feasibility and potential efficacy. Underpinned by realist programme theories situated within the UK Medical Research Council framework for development and feasibility phases of intervention development, three steps of the framework were iteratively followed. A systematic review (PhD Paper 1) identified the burden and correlates of faecal incontinence among older people living in care homes, and potential modifiable risks factors. A Cochrane systematic review of interventions for faecal incontinence in care homes (PhD Paper 2) did not find any intervention that accounted for the care home residents' characteristics or dementia. Therefore, some previously published realist programme theories were tested with care home stakeholders using realist evaluation approaches to develop an intervention for faecal incontinence that is context dependent. The intervention developed included toileting exercises (scheduled and prompted toileting), physical exercises (mobility and upper arms movement), conservative management (dietary and fluid intake, and review of polypharmacy) and staff education. Lastly, a pre/post feasibility study (nested in multiple case studies) was carried out in 16 care home residents from two care home units, all of whom had faecal incontinence at baseline and had dementia.

Results: Paper 1 included 23 studies and found the medians for reported prevalence of isolated faecal incontinence, double incontinence, and all types of faecal incontinence in care home residents as 3.5% [interquartile range (IQR) = 2.8%], 47.1% (IQR = 32.1%), and 42.8% (IQR = 21.1%), respectively. The Cochrane review (PhD Paper 2) included only four randomised controlled trials and found no clear evidence on what interventions work for this group. Stakeholder consultation was used to refine previous programme theories and then to develop an intervention. During feasibility testing of this intervention, the study was undermined by poor engagement by the care home staff. It was unclear what intervention had been carried out in one of the two units due to very poor documentation by the care staff. There was no overall significant difference in frequency of faecal incontinence episodes among the care home residents between baseline (four weeks prior to the intervention) and the last four weeks at the end of the 8-week intervention (mean and standard deviation (SD) of faecal incontinence episodes over the four weeks: 50.63 and 52. 94 (p=0.77). When the two care home units are compared, there were also no significant changes in the mean (SD) number of faecal incontinence episodes among the residents of Unit-1 and Unit-2 at baseline [52.50 (± 19.54) and 48.75 (± 20.31)], and four weeks to the end of the intervention [53.13 (± 23.33) and 52.75 (± 24.52)] respectively.

Conclusion: Although there were some changes in stool consistency among individual residents, the changes did not result in an overall reduction of faecal incontinence episodes in the participating care home units. In practice, unless regulatory bodies such as the Care Quality Commission include measures to reduce faecal incontinence (and as a safeguarding issue such as falls and pressure areas), or the care staff believe that incontinence among older people living with dementia in care homes can be ameliorated by intervention, the management of faecal incontinence is likely to remain as reactive measures by the care staff. Research in this context needs to be influenced by the care home managers who run the day-to-day activities of the care home, or risk implementation failure.

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COVID-19 IMPACT STATEMENT

The outbreak of COVID-19 pandemic has had a devastating impact on health and social care globally, but most specifically on the care homes in the United Kingdom (Cousins et al., 2020). Research published by the Office of National Statistics (ONS) shows that residents with a diagnosis of dementia or Alzheimer's disease were disproportionally affected, accounting for nearly half of care home deaths related to COVID-19 up to June 2020 (ONS, 2020). Alarmingly, it later became clearer that the death rate in the care homes had been underestimated; in fact, that the care homes death rate was higher than in hospitals (Booth, 2020a, ONS, 2020, Williamson, 2020). Of deaths involving COVID-19 among care home residents, 75% occurred within care homes and 25% occurred within hospitals (ONS, 2020).

The disruption caused by the COVID-19 pandemic impacted this PhD study. At the start of the pandemic outbreak, data collection for Phase-1 of the PhD study (Realist Evaluation – Chapter 6) had just begun. By then, one focus group discussion had been completed. Then the UK government announced national lockdown measures to contain the spread of the pandemic. All non-essential travels within the country were banned, and so too was visitation to care homes. The manager at the study site suspended all research activities for the first six months of the pandemic (March 2020 to August 2020). Meanwhile, from the start of the pandemic, I had travelled from England (where both my university and the study site are based) to join my family in Wales. The travel restrictions and restricted access to the study site resulted in inability to carry out further interviews as planned.

By September 2020 when the study site allowed research activities to resume, staff engagement resumed. However, on that occasion the care home Unit Managers advised minimal physical presence within the care home because they were struggling with COVID-19 infections among staff and residents, and the fact that I live in Wales which had its own local COVID-19 measures in place. Therefore, I scheduled several online meetings to carry out further recruitment and subsequent interviews (because some members of staff who were previously enrolled in the study had either left the job or were ill due to COVID-19 infection). The online meetings often were not carried out because the staff were either too busy or they forgot. I resolved these issues through arranged visitations during which further staff were recruited and interviewed.

From December 2020 to August 2021, I experienced personal challenges as the result of COVID-19 infection, and I was granted interruption of studies by my university. I resumed Phase-2 research activities (Feasibility study – Chapter 8) in September 2021 by visiting the care home once a week. At that time, four staff members who were previously appointed by the Unit Managers as "champions" to lead my study had been either promoted to senior positions in different units or had left the job. More importantly, the care home had undergone major reorganisation resulting in new managers running the two Units where the feasibility study was conducted.

The reorganisation of the care home to tackle the spread of COVID-19 infections and the COVID-19 restrictions again imperiled my ability to be present at the care home while the intervention was being conducted. This resulted in poor engagement by the care staff as reflected in poor documentation of the study activities. For example, one of the Units did not complete any paper care report forms for two weeks. This issue was eventually escalated to the Director of Nursing Services who was the leader of the Unit Managers, yet the poor engagement persisted throughout the intervention period.

Therefore, the intervention delivered, and results reported in the thesis should be considered taking into account the prevailing circumstances under which the study was delivered.

Author declarations

This thesis is entirely my own work and has not been submitted wholly or in part for academic award or qualification at any other educational institution. Parts of the PhD have been presented and published prior to submission of the thesis and these are detailed under ‘List of Papers’ below. This thesis is the result of my own independent work/investigation. Other sources are acknowledged by explicit references.

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I am extremely grateful to my eldest brother, Doctor Benedict Sele Musa, through whose love and benevolence I crossed the ocean from Liberia to Britain more than two decades ago. I am infinitely grateful to my parents, Mr Foday Musa and Mrs Sumor Sele Musa, farmer/tailor and housewife respectively. To my dad (may his soul rests in perfect peace), I have fulfilled your passion for education and your advice never to quit.

I am very grateful to the Abbeyfield Foundation for funding my PhD study.

List of papers

1. Musa, M.K., Vinsnes, A.G., Blekken, L.E., Harris, R.G., Goodman, C., Boyers, D., and Norton, C. 2018. Interventions for treating or managing faecal incontinence in older people living in care homes (Protocol). *Cochrane Database of Systematic Reviews 11*, CD013200.

2. Musa, M.K., Saga, S., Blekken, L.E., Harris, R., Goodman, C., and Norton, C. 2019. The Prevalence, Incidence, and Correlates of Fecal Incontinence Among Older People Residing in Care Homes: A Systematic Review. *Journal of the American Medical Directors Association 20(8)*, 956-962.

3. Musa, M.K., Vinsnes, A.G., Blekken, L.E., Harris, R.G., Goodman, C., Boyers, D., and Norton, C. 2022. Interventions for treating or managing faecal incontinence in older people living in care homes (Review). *Cochrane Database of Systematic Reviews,* ***Submitted for publication.***

LIST OF ABBREVIATIONS

ADLs	Activities of daily livings
ANP	Advanced Nurse Practitioner
C	Context
CHs	Care homes
CI	Confidence interval
CMO	Context-mechanism-outcome
CQC	Care Quality Commission
CTT	Colonic transit time
DI	Double incontinence
FI	Faecal incontinence
FINCH	**F**aecal **in**continence in people with advanced dementia living in **c**are **h**omes
GP	General Practitioner
HR	Hazard ratio
ICS	International Continence Society
iFI	Isolated faecal incontinence
IM	Intervention mapping
ImFaCON	**Im**proving **Fa**ecal **CON**tinence
IQR	Interquartile range
LTCF	Long-term care facilitates
m	Mean
M	Mechanism
MDS	Minimum dataset
MRC	Medical Research Council
NHS	National Health Services
NIHR	National Institute for Health and Care Research
NICE	National Institute for Health and Care Excellence
O	Outcome
ONS	Office of National Statistics
PCC	Person-centred care
PCCS	Person-centred care software
PT	Programme Theories
QoL	Quality of life
RCT	Randomised controlled trial
RE	Realist evaluation
RIP	Rest in peace
RN	Registered Nurse
SD	Standard deviation
TIDieR	Template for Intervention Description and Replication
TPNS	Transcutaneous Posterior Tibial Nerve Stimulation
UI	Urinary incontinence
UK	United Kingdom
UN	United Nations
USA	United States of America

PART ONE

Part-1 of this thesis concentrates on the knowledge basis for the research topic: what is already known and what are the gaps in the literature (Chapter 1), and two reviews to investigate the gaps in the literature (Chapters 2 and 3).

Chapter 1: Introduction

This chapter delineates available knowledge on faecal incontinence (FI) and unravel the gaps in the literature concerning faecal incontinence. It commences with a discussion of background information on the research topic and then outlines the operational definition of FI, its aetiology, and epidemiology among older people. The chapter explores what a care home is, the characteristics of its residents and workforce, the emotional labour involved in caring activities, and some challenges to be aware of when conducting research within the care home environment. The chapter concludes by providing an overview of the structure of the thesis.

1.1 Background to improving faecal continence study

Being incontinent of faeces is distressing for any adult to experience. Faecal incontinence (FI) is characterised by the incapacity to appropriately control the bowel, resulting in leakage of faecal material that is a hygiene problem (Haylen et al., 2010, International Continence Society (ICS), 2015, National Institute for Health and Care Excellence (NICE), 2007b). Many people with the condition may refer to it as diarrhoea (Bharucha et al., 2022). Depending on the mechanism of FI, it may be described as: faecal soiling – the leakage of stool following normal evacuation; passive incontinence – an involuntary discharge of stool without awareness; urge incontinence – discharge of faecal matter despite attempts to retain bowel contents; and functional incontinence – a voluntary incontinence due to functional limitation to reach a toilet facility in time to appropriately empty the bowel (Jerez-Roig et al., 2015, Rao and American College of Gastroenterology Practice Parameters, 2004).

Faecal incontinence remains a taboo subject despite its recognition for many decades ago (National Institute for Health and Care Excellence (NICE), 2007b, Norton, 2004). It is a taboo subject because it is unlikely to be raised by individuals and the topic may be avoided by health professionals (Yates, 2021). It can occur at any age, but it is more prevalent among older people population (Macmillan et al., 2004, Ng et al., 2015, Roberts et al., 1999, Sharma et al., 2016) compared with younger people (de Souza Santos and Santos, 2011, Rajindrajith et al., 2013, Siproudhis et al., 2006). Its prevalence among older people living in institutionalised settings such as care homes (e.g., nursing and/or residential care settings, or aged care setting, or skilled nursing facilities) is higher still (Ihnat et al., 2016, Leung and Schnelle, 2008, Saga et al., 2013), compared with the same age group living within community settings (Bharucha et al., 2005, Ng et al., 2015, Pretlove et al., 2006, Whitehead et al., 2009, Whitehead et al., 2020). An explanation for the higher prevalence of FI among older people living in care homes is that there are usually multifactorial interacting risk factors for FI among care home residents who are frail, and have age-related physiological changes, often have multiple comorbidities, are receiving multiple pharmacological treatments, and often experiencing cognitive decline (Barker et al., 2020, Cognitive Functioning and Aging Studies (CFAS), 2022, Green et al., 2017, Maher et al., 2014, Matthews et al., 2005, Richardson et al., 2019).

Preventing and/or managing FI among older people living in care homes is a significant and persistent challenge for staff and visiting clinicians (Goodman et al., 2017). One reason for this is that incontinence care is often considered as “dirty work” (Dahle, 2005) because it is bodily intimate and often involves the ‘negativities of the body’ (Meldgaard Hansen, 2016). From the perspectives of the general public, for example, faecal incontinence evokes feelings of disgust and images of frailty, disintegration, incompetence and old age (Ostaszkiewicz et al., 2016a). These emotions tend to cause most people to distance themselves from incontinence care (Lopez, 2006, Ostaszkiewicz et al., 2016a). However, care workers whose work is grounded in care of other peoples’ bodies have to find a way to provide continence care affectively and behaviourally (Ostaszkiewicz et al., 2016a). In a survey to determine the effects of FI on healthcare providers’ decision to refer patients for care home placement, Grover and colleagues found that dealing with FI is associated with increased caregiver burden, which may affect staff turnover and morale (Grover et al., 2010). This finding is an important factor which potentially undermines FI management within a care home setting where the workforce is already low paid and often receives little clinical support (Donald et al., 2008, Hussein and Manthorpe, 2014, Ostaszkiewicz et al., 2016a).

The current treatment of FI for older people living in care homes is multifactorial, including psychological support, behavioural therapies, drug therapies, surgery, and containment products (Andrews and Bharucha, 2005, Blekken et al., 2015a, Bliss et al., 2010, Brocklehurst et al., 1998, Flanagan et al., 2014, Norton et al., 2010). Nursing management of FI is mainly the use of containment products such as disposable, or reusable pads and pants which are seen as the best options for managing FI (Ijaola, 2010, Leung and Schnelle, 2008, Li et al., 2022). However, these methods often cause the skin to come into contact with excrement (Mugita et al., 2021), which can potentially lead to skin damage or even skin disease (Li et al., 2022). This 'pad culture' has also been recognised in acute hospital setting providing continence care to patients with dementia (Featherstone et al., 2022). In their study, Featherstone and colleagues (2022) found an ingrained pad culture where by continence pads were routinely used in patients with dementia regardless of their level of continence at admission to hospital. Meanwhile, continence care for older people living with dementia is recognised by policy makers as a key factor associated with poor experience and outcomes for people living with dementia (Alzheimer's Society, 2021b, Department of Health, 2006, National Institute for Health and Care Excellence (NICE), 2018).

There are national and international guidelines for management of FI, which recommend that managing FI should generally start with patient education, dietary modifications, skin care, and pharmacologic agents to modify stool delivery and consistency, followed by pelvic floor muscle rehabilitation with biofeedback (National Institute for Health and Care Excellence (NICE), 2007b, National Institute for Health and Care Excellence (NICE), 2021, Savarino et al., 2022). The NICE guidelines on management of FI in adults, for example, recommend taking a history of patients' dietary and fluid intake, underlying medical conditions, medication, mobility and exercise (National Institute for Health and Care Excellence (NICE), 2014, Norton, 2004). Some interventions are believed to improve or resolve symptoms of FI in 50% to 80% of patients outside of care homes (Wald, 2016, Wald et al., 2014). However, the NICE guidelines are for the general adult population and arguably taking a patient's history alone will not resolve much of their FI problem. The NICE guideline was specifically written for adults attending primary care and National Health Services (NHS) hospitals, and not specific to address the needs of frail, older people living with dementia in the care home settings. Currently, uptake of the NICE continence care guidelines within the care home sector is unknown. In 2012, a care home continence audit carried out in the UK identified ageism, lack of staff training, restrictions of pad usage because of cost control, and poorly integrated services as contributory factors for low standards of care for FI (Harari et al., 2014). Therefore, there is an exigent need for an alternative continence care that takes into consideration the characteristics of the care homes population such as frail, older people living with dementia and the impact of the care home environment on continence (Goodman et al., 2017). Crucially, there is a need to understand what constitutes faecal incontinence.

The next section outlines the operational definition of faecal incontinence in this thesis.

1.2 Defining faecal incontinence

There is no consensus definition of faecal incontinence (FI) in the literature (Bharucha et al., 2022). While some authors define FI as involuntary leakage of stool (liquid and solid forms) and flatus (Aslan et al., 2009), others define the term by limiting the 'involuntary leakage' to liquid and solid stool (Bliss et al., 2013, Jerez-Roig et al., 2015, National Institute for Health and Care Excellence (NICE), 2014, Norton et al., 2010). One can justifiably argue that the inclusion of 'flatus' in FI definition is misleading because it makes differentiating health from illness almost impossible. Flatus often occurs in many healthy people (Whitehead et al., 2009). It is also very difficult, if not impossible to account for number of episodes of flatus per month, week, or day. Another crucial point that warrants consideration in various FI definitions is the reference to the 'involuntariness of faecal leakage.' First, it is possible for one to voluntarily become incontinent due to several factors such as being physically unable to reach toilet facility because of functional limitation (i.e., neurological deficit), or simply because there is no toilet facility to use when the need arises (i.e., absence of an enabling environment). In the case of residents in care homes, it may also be due to poor practice (e.g., strict application of health and safety rules that restrict mobility of residents even when the need to use toilet facilities arises).

In research, there has been a challenge in terms of how FI is measured. While some studies have considered frequency of FI per week or month, others have defined FI as "leakage of stool at least few times a day" (Saga et al., 2013). Another challenge is also whether to include 'smearing of undergarments' when measuring FI as suggested by the Rome IV criteria (Rao et al., 2016). While smearing of an undergarment may be indicative of FI, it may also be due to other reasons such as improper hygiene, or lack of providing proper care (in cases of residents unable to clean themselves after defaecating). Thus, it can be argued that the inclusion of parameters such as 'smearing of undergarments' in the definition of FI has the propensity to introduce ascertainment bias in study results.

Therefore, taking all the above controversies regarding definition and measurement of FI, the operational definition of FI adopted for this thesis, hereinafter, is a recurrent, involuntary expulsion of faecal material (liquid or solid stool) through the anus, or knowingly defecating before reaching toilet facilities due to functional limitations in a person of developmental age of at least 4 years old who has previously achieved control of bowel movements, with episodes of leakage lasting for at least 1 month (Department of Health (DH), 2000, Duelund-Jakobsen et al., 2016, Norton et al., 2010, Paquette et al., 2015). The condition of FI must be recurrent (also includes intermittent), as there is no justification to include one-off incontinence which might have occurred due to lack of a toilet facility. The condition may occur consciously or without any awareness depending on the mechanism of incontinence. This FI operational definition encompasses multiple causes that may include constipation, cortical atrophy, neuropsychological, sensory disability, physical disability (mobility and dexterity), medication effects (sedatives, antidepressants, and diuretics) and psychological factors (personality, habits, life experience and mood). All of these can be compounded by the built environment, for example distance to the toilets, obstacles, visual access, signage, and the actions and attitudes of others.

The extent to which FI affects older people in general, and more specifically those living in care homes, is considered in the next section.

1.3 The impact and risk factors of faecal incontinence

FI is strongly associated with lower self-esteem and negative quality of life (QoL) (Bharucha et al., 2022), and it may be a source of institutionalisation, or social isolation for people who experience it (Bucher, 2020, National Institute for Health and Care Excellence (NICE), 2007b). It is a stigmatising health condition that affects dignity (Nelson et al., 2009, Norton et al., 2010). Many people with the condition are generally embarrassed or ashamed to discuss their problem with healthcare professionals, or even with friends and family (Bucher, 2020); healthcare practitioners too do not routinely broach the FI topic during consultation with patients (National Institute for Health and Care Excellence (NICE), 2007b, Norton et al., 2010). This may be because healthcare workers lack knowledge about availability of treatment for FI and are, therefore, reticent to mention it (Madoff et al., 2004). Research has shown that the term “faecal incontinence” is used by caregivers to communicate with each other, but it is either misunderstood, or avoided by patients because of embarrassment (Brown et al., 2012, Whitehead et al., 2009). Many patients prefer the term “accidental bowel leakage” making the diagnosis often cumbersome (Whitehead et al., 2009).

FI is a “silent affliction” (Johanson and Lafferty, 1996), meaning that people who experience it do not like to talk about their experience. This can lead to feelings of shame and embarrassment and to a downward spiral of psychological distress, dependency, and poor health among people who experience FI (Blekken et al., 2015a, National Institute for Health and Care Excellence (NICE), 2014, Norton, 2004). It may cause pressure ulcers and dermatitis which can be distressing due to discomfort and pain (Flanagan et al., 2014). This may particularly impact older individuals’ functional status (e.g., impairments in activities of daily living (ADL)), quality of life (QoL), and unplanned hospital admission (Deb et al., 2020). It has been reported that FI has strong correlation with increased mortality among older people in care homes (Chassagne et al., 1999).

In addition to psychosocial consequences of FI, there are also financial consequences involved in managing the condition. An estimated 2% of the total UK NHS annual budget is spent on continence care (both FI and urinary incontinence) among adults (National Institute for Health and Care Excellence (NICE), 2007b). More than a decade ago, the cost of care for older people’s continence needs was reported as approximately £500 million per annum, and the cost of older peoples’ continence care included £27 million for continence products, £58 million for appliances such as faecal collectors and anal plugs, and £22 million for drugs (NICE, 2007). There are no recent estimates of the cost of treating FI in older adults in the UK. In view of current inflation and high demand for healthcare resource use, the current cost for management of FI in the UK is likely at least twice as the figures reported by NICE in 2007. There is evidence that managing FI is time consuming for caregivers and that it poses a professional challenge to caregivers who are required to employ emotional labour (Badolamenti et al., 2017, Gray, 2009) presumably because faecal matter is socially unacceptable (Whitehead et al., 2009).

Faecal incontinence is a sign or symptom, rather than a diagnosis (NICE 2007). From a biomedical perspective, the aetiology of FI is multifactorial (Table 1.1). The causes of FI include modifiable risk factors (e.g., diet, poly-pharmacology, inadequate resources, and dysfunctional work culture, etc.) and non-modifiable risk factors including functional impairments (e.g., dementia, Parkinson disease, stroke, spinal injuries, diabetes, etc.) and physical limitations (vision impairment, frailty, limited access to toileting assistance, etc.) (Table 1.2). Hence, it is important to diagnose the underlying cause of FI for individuals to manage the FI condition most effectively (NICE, 2007).

Table 1.1: Summary aetiology of faecal incontinence

Description	Examples
Neurological factors	Dementia Parkinson’s disease Multiple sclerosis Stroke Diabetic mellitus Spinal bifida Pudendal neuropathy (Alcock canal syndrome)
Faecal impaction with overflow	Low fibre diet Poor fluid intake Immobility Medications such as Codeine phosphate, opioids
Anal sphincter damage, weakness or degeneration	Obstetric trauma: instrumental delivery, large baby Post-surgery: anal stretching, haemorrhoidectomy Direct trauma Radiotherapy for cervical or pelvic neoplasm
Diarrhoea and intestinal injury	Ulcerative colitis Crohn’s disease Irritable bowel syndrome
Environmental factors	Ability to reach toilet in time Access to toilet facilities Laxative induced or side effects of medication
Congenital	Imperforate anus Cloacal defects Rectal agenesis Myelomeningocele
Anorectal pathology	Rectal prolapse Anal fistula or fissure Cancer

Sources: (Ijaola, 2010, Madoff et al., 2004, National Institute for Health and Care Excellence (NICE), 2007b)

Faecal incontinence among older people is not due only to old age because the reason for the FI could be due to other factors such as functional disability (Table 1.2).

Table 1.2: Summary of psychosocial causes of FI

Functional disability	Effect on the bowel
Cognitive impairment	Poor recognition or memory of the toilet's location, or how/why to ask for assistance.
Reduced mobility	The person is unable to get out of a chair independently or to reach the toilet unaided.
Communication difficulties	The person is unable to express their need to use the toilet.
Poor vision	The person is unable to see the whereabouts of the toilet.
Limited dexterity	The person is unable to pull down zips or fasteners or adjust clothing in time.
Unsuitable environment	Inaccessible toilets, poorly sign posted toilets.
Healthcare worker related	The unavailability of a healthcare worker or call bell; healthcare worker negative attitude to toileting.

Source: (Adegbola and Donnelly, 2010)

Therefore, several underlying causes of FI may be treated or managed effectively, especially those that relate to functional disability (Bharucha et al., 2022, Blekken et al., 2015c, Seigneurin-Hérissé et al., 2022). For example, for people living with dementia who are unable to control defaecation due to lack of cortical control, scheduled or prompted toileting has been found to increase dependently continent bowel movements (Ouslander et al., 1996a). It has also been observed that positive reinforcement of FI (i.e., offering incontinence pads to care home residents) may reduce toileting opportunities and exacerbate incontinence (Saga et al., 2014).

As well as the risk factors described in Table 1.1 and Table 1.2 above, constipation is also one of the risk factors that may lead to FI. Constipation is one of the most common health problems encountered by older people in general, and specifically in those with dementia because they might not be able to express the pain and discomfort of the constipation verbally (Chen et al., 2020). The consequence of the older person with dementia not being able to communicate constipation may sometimes manifest as aggressive behaviour to caregivers, often leading to inappropriate administration of anti-psychotic drugs (Resnick et al., 2021, Shaw et al., 2018a, Almutairi et al., 2018), which can only make matters worse because such drugs can potentially cause or exacerbate constipation (Xu et al., 2021, van

Dijk et al., 1998, Every-Palmer et al., 2017, Al-Jumaili and Doucette, 2018). Therefore, the need for caregivers to understand potential contributing factors for constipation and the impact of dementia on the person's ability to communicate their needs is paramount for an intervention aiming to reduce FI in this population.

Broadly, there are two major types of constipation: slow transit type, in which the movement of faecal material through the colon is slow; and outlet obstruction type, in which the patient has trouble evacuating rectal contents (Cheung and Wald, 2004). Outlet obstruction, secondary to pelvic floor dysfunction, accounts for 50% or more cases of constipation in adults (Olsen and Rao, 2001, Steele and Mellgren, 2007, Talebi et al., 2020). Colonic motility dysfunction, or dysmotility, is failure of coordinated motor activity to move stool through the colon (Levin, 2021, McCrea et al., 2008). It is sometimes associated with dietary factors, medications that can alter motility, or systemic disease (e.g., neurologic, metabolic, or endocrine disorders) (McCrea et al., 2008). Dysmotility results in colonic delay (e.g., abnormally prolonged colonic transit time) (Liu et al., 2022). Three types of colonic delay have been identified: right colonic (colonic inertia), left colonic, and rectosigmoid (Wedel et al., 2002). Mechanisms of colonic delay include dysfunction of the autonomic nervous system (ANS), disruption in the neuroendocrine system (McCrea et al., 2008), and/or colonic myopathy (Knowles et al., 2001).

The second mechanism involves pelvic floor dysfunction, or disorders of the anorectum and pelvic floor, which result in outlet dysfunction and an inability to adequately evacuate rectal contents (Levin, 2021). Both mechanisms coexist in some patients, making it difficult to determine the exact underlying mechanisms for constipation (Cheung and Wald, 2004). Different terms that are used to describe these disorders include anismus, pelvic floor dyssynergia, paradoxical pelvic floor contraction, paradoxical puborectalis muscle contraction, paradoxical sphincter contraction, obstructed defecation, functional rectosigmoid obstruction, and functional faecal retention (Bouchoucha et al., 2019, Olsen and Rao, 2001, Pezim et al., 1993). The pathophysiology of these disorders is not completely understood (McCrea et al., 2008).

In older people, constipation is multifaceted, and may include mechanical, biologic, and macroscopic changes in the gastrointestinal (GI) tract that occur during the aging process, which can affect bowel structure and function, resulting in slow colonic transit time (CTT) and pelvic floor disorders (McCrea et al., 2008). The average CTT in someone who is not constipated is 30 to 40 hours, which can increase up to 72 hours and still be considered normal. However, CTT in women is generally higher, and may reach up to around 100 hours (Cho et al., 2013). Therefore, determining strategies to ameliorate constipation requires the exploration of factors associated with CTT (Yurtdaş et al., 2020).

Some factors that affect the CTT include age, gender, body mass index (BMI), dietary fibre and water intake, physical activities, and certain types of medication (Cho et al., 2013). Among these factors, only those that are potentially amendable to intervention by care staff (e.g., dietary fibre and water intake, physical activities, and medication usage) will be included in the intervention in this thesis.

The next section outlines the prevalence of FI among older people in general, and most specifically older people living with dementia.

1.3.1 Global aging and FI problems among older people

Faecal incontinence is more prevalent in older people. With reports of an aging population (World Health Organisation (WHO), 2021), the number of older people experiencing faecal incontinence is likely to increase. The reason for this is that with advanced age comes multiple comorbidity and frailty, thus leading to dependence on caregivers for support in activities of daily living (ADLs). Evidence suggests that the number of older individuals with "geriatric syndromes" including frailty, cognitive impairment, and incontinence is projected to increase over the next 20 years because more people are living up to 85 years and above, and these individuals often have higher levels of dependency due to underlying comorbidities (Kingston et al., 2018). It is estimated that approximately 35% of the European population and 28% of the North American population are expected to be aged 60 years or over by 2050 (UN Department of Economics, 2017). In the UK, report suggests that over the next two decades, there will be about 4.75 million people aged 65 years and above, that is approximately 48.9% growth in this subgroup of the UK population (ONS 2016).

The UK Office of National Statistics report confirms that increasing life expectancy does not necessarily equate to healthy life expectancy (Age UK, 2017, ONS 2016). In other words, while some of the older people live healthily at homes (and in care homes), many older people live with complex health needs that often require multifaceted interventions (Franceschi et al., 2018, Jaul and Barron, 2017).

Understanding normal and abnormal physiology of the human bowel is a significant step in developing interventions to manage bowel dysfunctions. The next section outlines the anatomy and physiology of the human bowel.

1.4 The anatomy and physiology of the human bowel

The human bowel is a long, tube-shaped, muscular organ in the abdomen that completes the digestion process (Figure 1.1). It is part of the digestive or gastrointestinal system that is designed to help the body absorb nutrients and fluids from ingested food and drink (Ma and Lee, 2020). When ingested food enters the small intestine, the bile produced by the liver and enzymes produced by the small intestine and the pancreas continue the process of digestion (Volk and Lacy, 2017). The smaller molecules (e.g., monosaccharides, amino acids, bile salts, vitamins, and other nutrients) are then absorbed into the blood stream through the epithelial cells lining the walls of the small intestine (Campbell et al., 2019). The small intestine is the longest part of the gastrointestinal tract and can be divided into three parts: the duodenum, jejunum and ileum (Cleveland Clinic, 2022). It is approximately 6m (19.7ft) in the average person and assists in the digestion and absorption of ingested food and fluid (Denbow, 2015, Derrickson and Tortora, 2014, Ma and Lee, 2020). The undigested food is moved to the colon from the ileum via peristaltic movements. The ileum ends and the large intestine begins at the ileocecal valve (Campbell et al., 2019, Volk and Lacy, 2017).

The large intestine reabsorbs the water from indigestible food material and processes the waste material (Barleben and Mills, 2010, Nigam et al., 2019). The large intestine includes the caecum, colon, rectum and anal canal, and is about 1.5m (4.9ft) long muscular tube (Greenwood-Van Meerveld et al., 2017). The large intestine delivers stool to the rectum where it is stored until defaecation (Figure 1.1). The faeces are propelled using peristaltic

movements during elimination (Derrickson and Tortora, 2014, Nigam et al., 2019).
The anus is an opening at the far-end of the digestive tract and is the exit point for the waste material (Figure 1.1).

The consistency of the stool is dependent upon many things, including how long the stool sits in the colon, how much of the water has been absorbed from the waste, and the amount of fibre and fluids in the diet (Phillips, 1969). Stool consistency can vary from hard lumps to mushy to very loose, watery stool (Continence Foundation of Australia, 2020). The best and easiest consistency of stool to pass is soft, like toothpaste (Continence Foundation of Australia, 2020).

The normal colon has five main functions (Greenwood-Van Meerveld et al., 2017, Phillips, 1969, Sulaiman and Marciani, 2019), among which are:

1. **Storage:** the colon stores unabsorbed food residue. Within 72 hours, 70% of this has been excreted. The remaining 30% can stay in the colon for up to a week.
2. **Absorption:** sodium, water, chloride, some vitamins, and drugs, including steroids and aspirin, are absorbed from the colon.
3. **Secretion:** mucus is secreted and used to lubricate the faeces.
4. **Synthesis:** a small amount of vitamin K is produced.
5. **Elimination:** peristaltic movement of faecal matter into the rectum, where its presence is detected by sensory nerve endings and a sensation of fullness is experienced, followed by a desire to defaecate.

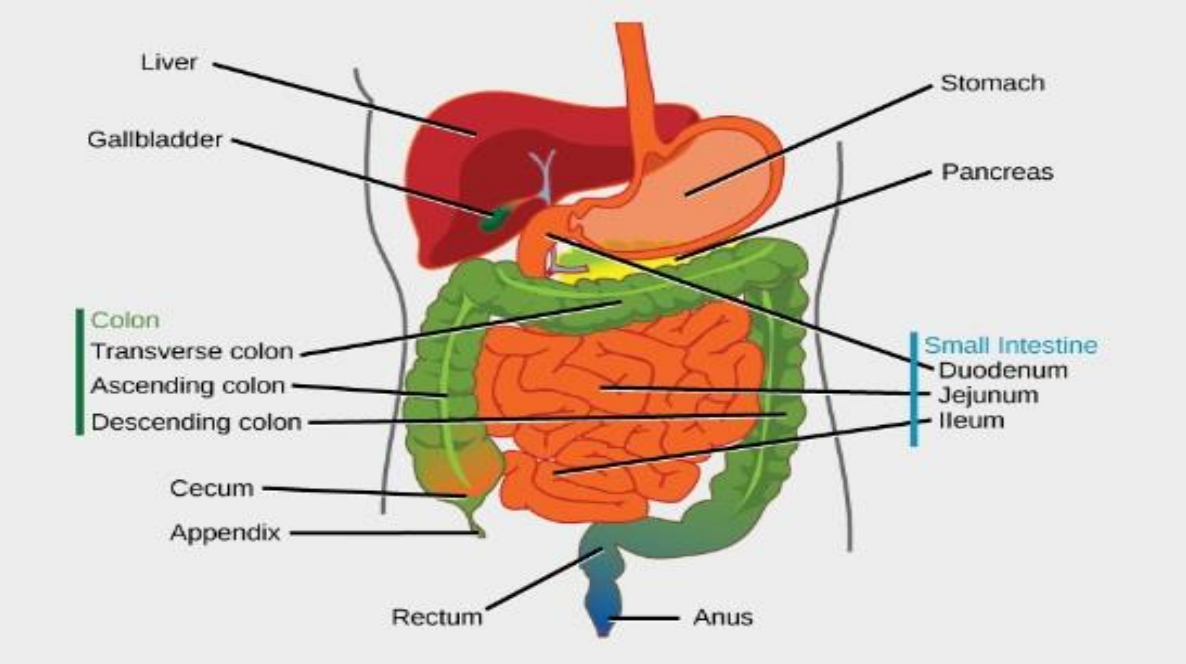

Figure 1.1: The anatomy of the human bowel

Credit: https://openstax.org/books/concepts-biology/pages/16-2-digestive-system

Defaecation (the discharge of waste matter from the large intestine) is the last stage of the digestive process when food has passed through the digestive tract (Greenwood-Van Meerveld et al., 2017, Phillips, 1969, Sulaiman and Marciani, 2019). The passage of stool through the gastrointestinal tract may not always be normal (Barleben and Mills, 2010, Denbow, 2015, Derrickson and Tortora, 2014). For example, constipation occurs when stool passes through the large intestine too slowly; and diarrhoea happens when faeces pass through the large intestine too quickly (Greenwood-Van Meerveld et al., 2017). Abnormal bowel movement (or defaecatory disorder) (Deb et al., 2020) may result from abdominopelvic discoordination, which results in decreased rectal propulsive forces and/or increased resistance to evacuation (Rao et al., 2016). Other disturbances (e.g., reduced rectal sensation (Bharucha et al., 2005) and anatomical abnormalities (e.g., large rectocele) may contribute to problems with defaecation (Deb et al., 2020). In older people, excessive straining can weaken the pelvic floor increasing the risk for excessive perineal descent (Henry et al., 1982, Pucciani, 2018), rectal intussusception (Parks et al., 1977, Pigalarga and Patankar, 2021), and pudendal neuropathy which in turn can increase the risk of FI (Andrews and Storr, 2011, Deb et al., 2020).

The speed at which food moves through the digestive system varies. Depending on the type of food present, it can take an average of one to three days to process, up to 90% of that time being spent in the colon (Roager et al., 2016). Normal bowel habits range from 3 times a day to 3 times a week (Tresca, 2021). Not everyone will have a bowel movement daily. Some people have difficulty moving food through the colon. This is known as slowed or delayed colonic transit time (CTT) (Bharucha et al., 2019). Sometimes taking medication to speed up CCT can assist these people with delayed CCT (Müller et al., 2020).

Defaecation is a complex process that involves coordination of many different muscles and nerves (Figure 1.2). There are two major muscles the stool must pass through to exit the anus, the internal sphincter muscle, and the external sphincter muscle. The internal sphincter muscle is “involuntary”. It automatically relaxes and opens at the top of the anal canal to allow stool to pass through. As the stool enters the upper anal canal, it is “sampled” by the sensitive nerve cells. People with normal nerve sensation have the urge to have a bowel movement. The external sphincter muscle is a “voluntary” muscle; one has control over this muscle. It assists in keeping the stool in the rectum until the person is ready to have a bowel movement. In fact, squeezing the external sphincter muscle pushes the stool back up out of the anal canal and the rectum relaxes. The urge to have a bowel movement is gone until the next colon contraction reaches the rectum. Frequent holding of stools can cause constipation and desensitisation of nerve cells. The longer the stool remains in the colon and rectum, the more fluid is absorbed, and the harder the stool becomes.

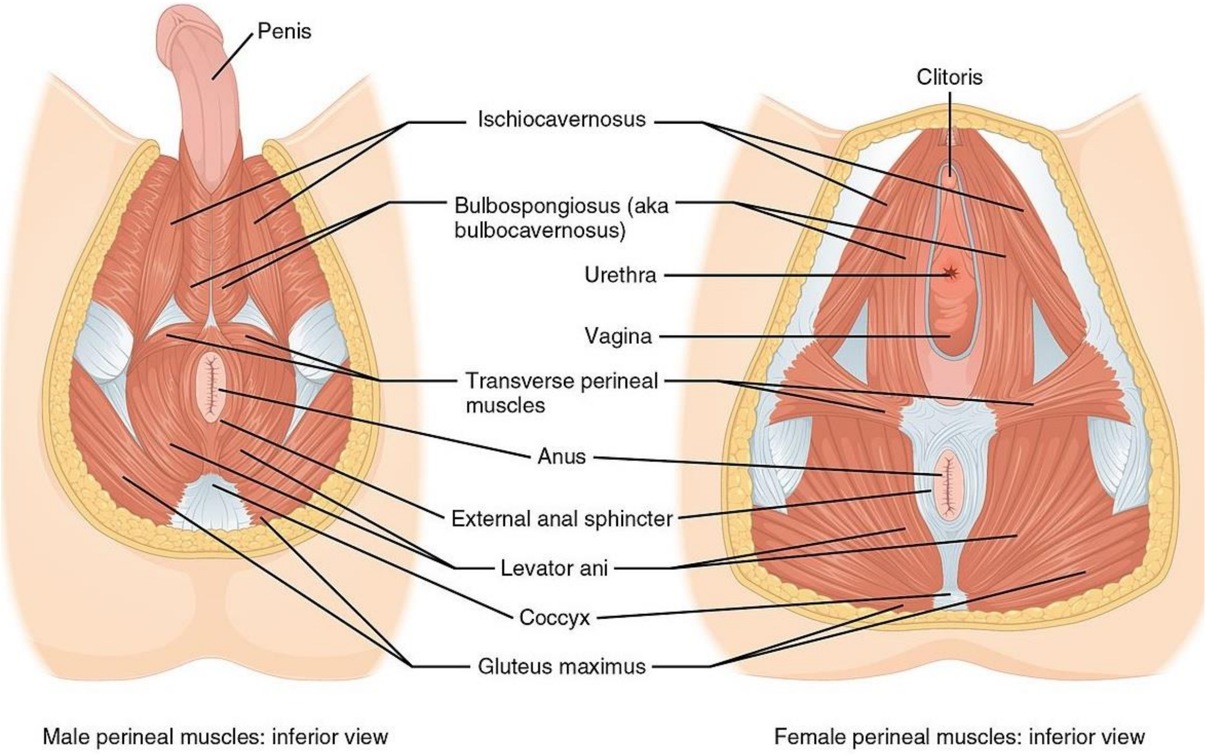

Figure 1.2: The pelvic floor muscles

Credit: OpenStax

https://commons.wikimedia.org/wiki/File:1116_Muscle_of_the_Perineum.jpg

The ability to retain and expel stool is dependent on the muscles of the pelvic floor (Figure 1.2). The pelvic floor muscles help keep the pelvic viscera in place and prevent them from being pushed through the pelvis during straining (Gowda and Bordoni, 2021). They achieve this by being unconsciously contracted at rest and can be consciously contracted during times of raised intra-abdominal pressure (vomiting, sneezing, coughing, lifting a heavy object, or forced expiration). The pelvic floor muscles are collectively referred to as the *levator ani* and *coccygeus* muscles (Gowda and Bordoni, 2021). They form a large sheet of skeletal muscle that is thicker in some areas than in others. The muscles are attached along the inner walls of the true pelvis to a condensed area of the obturator fascia known as the *tendinous arch of levator ani muscle* (Corton, 2009*)*. The levator ani is made up of the puborectalis, pubococcygeus, and iliococcygeus muscles (Corton, 2009, Gowda and Bordoni, 2021).

The *levator ani muscles* arise from the pelvic sidewalls and run downward to form a funnel in the pelvis, helping to support the anal canal, the urethra and in women, the vagina (Corton, 2009). Contraction of the *levator ani muscles* aid in maintaining both urinary and faecal continence until it is convenient to void. This is best demonstrated by the *puborectalis muscle*, which provides a ring of support around the anal canal at the small end of the funnel made by the *levator ani muscle*. It has a “U” shape creating an angle between the anal canal and the rectum. Under resting conditions this angle is 90°, but during straining and moving the bowels this angle moves to 135° (Casey and Temme, 2017, Prather et al., 2009).

FI occurs when patients develop bowel disturbances, typically diarrhoea, which overcome the anorectal continence barrier and/or develop anorectal sensorimotor dysfunction (that is, anal weakness, a stiff and/or small rectal reservoir, and increased or reduced rectal sensation) (Bharucha et al., 2022).

The next section outlines the prevalence of FI within both care homes and community settings.

1.5 Epidemiology of FI in Care Homes: the “silent affliction”

Throughout this thesis, the term "care home” (CH) is a generic term that is used to refer to 24-hour care facilities such as residential care settings where a number of older people live together and have staff available 24 hours a day to provide personal care (without the need for on-site registered nurse; e.g., residential homes), and/or care facilities where a registered nurse is required on duty 24 hours to provide additional nursing care for more dependent residents with underlying medical condition (e.g., nursing homes) (Underwood et al., 2013). Where there is a need to emphasise a specific type of care home setting (e.g., residential or nursing home), it will be acknowledged in brackets. The term “care home” has been adopted in this thesis because this term has been used by several guidelines and policy documents within the UK (Care Quality Commission (QCQ), 2022, Department of Health (DH), 2013, National Health Services (NHS), 2020). Care homes generally exist to serve the older population who have some form of medical conditions and/or vulnerabilities that require nursing care (Sanford et al., 2015), although some also (or exclusively) care for younger people with care needs.

The true prevalence of FI among care home residents worldwide is unknown (Madoff et al., 2004). The reasons for dearth of global epidemiological knowledge about FI include under-reporting of symptoms by patients, lack of knowledge among healthcare workers about treatment options, dissonance of FI definition (some researchers measuring outcome in terms of severity, while others measure FI based on frequency per days, weeks, or even months), and differences in data collection methods (Aslan et al., 2009, Madoff et al., 2004). There is an inherent subjectivity that leads to under-reporting of FI because of the underlying social embarrassment about uncontrolled faecal expulsion (Bucher, 2020, Horrocks et al., 2004). People may not want to be known for leaking of faeces and may therefore give a socially desirable answer when questioned about their bowel problems (Andrews and Bharucha, 2005). Some people may not even admit that they suffer from FI because they consider it as a natural process of aging (Aslan et al., 2009), or simply a lack of awareness that treatments are available (Horrocks et al., 2004).

In one study conducted in the United Arab Emirates, it was found that approximately 60% of women with FI did not seek advice from health professionals because of embarrassment and hope that the situation would resolve spontaneously (Rizk et al., 1999). Another study conducted in the USA across five care homes [described as nursing homes] reported that 46% of the care home residents (n=388) were faecally incontinent (Johanson et al., 1997). A study on the prevalence and demographic distributions of FI found that a third of the patients reportedly discussed their FI problems with their health professionals (Johanson and Lafferty, 1996). The same authors also reported that FI was about 1.3 times more common among males and people younger than 65 years old (Johanson and Lafferty, 1996).

However, contrary to the latter finding by Johanson and colleagues, several studies have reported the prevalence of FI in care homes to be highest among the older populations (people aged 65 years and above), particularly among females (Blekken et al. 2016; Javier et al. 2015; Saga et al. 2013). However, one study found no significant difference between women (9.4%) and men (7.3%) experiencing FI in the community setting (Ditah et al., 2014). The studies reported since 1986 have found the prevalence rate of FI in care homes to range from 6% to 54% (Blekken et al., 2016, Tobin and Brocklehurst, 1986). Interestingly, more recent epidemiological studies have shown higher FI prevalence rate in care homes, unlike older studies that reported a lower FI prevalence rate (Blekken et al., 2016, Nelson et al., 1998, Saga et al., 2013). One explanation for finding high FI prevalence rates among older people in recent studies may be due to the aging population, with increasing frailty and dependency in the care home population. Another reason could be that more people have become aware of the existence of the condition and are perhaps feeling more confident to talk about it.

Evidence suggests that FI is one of the most commonly cited reasons for care home admission (Kang et al., 2012). Since 1986, only one UK study has explored epidemiology of FI among care home residents and it reported the FI prevalence rate as 10.3% (Tobin and Brocklehurst, 1986). It is rather surprising to note that the UK has not undertaken further epidemiological study for more than three decades to explore this “silent affliction” notwithstanding the aging UK population, increased care home population, and comorbidities among the care home residents. Therefore, there is exigent need for research to determine the true prevalence of FI in UK care homes to help develop effective and sustainable continence care.

Firstly, however, knowledge about FI prevalence within the community setting is vital because many people admitted within the care home setting start experiencing FI while living at home.

1.6 Prevalence of FI in the community

Generally, population-based studies have estimated the prevalence of FI to range from 0.004% to 18% (Blekken et al., 2016, Ihnat et al., 2016, Johanson and Lafferty, 1996). A systematic review examined published articles from 1966 to February 2015 on prevalence of

FI in community-based adults and reported that the prevalence of FI varied from 1.40 to 19.50% (Sharma et al., 2016). This FI prevalence is consistent with a previous systematic review which reported FI prevalence to range from 2.0 to 20.70% (Ng et al., 2015). A relatively recent National Gastrointestinal Survey of community older people in the United States of America (n=71,812) reported FI prevalence to be 14.40% (Menees et al., 2018). In the same survey, older age, male sex, and Hispanic ethnicity were reported to increase the likelihood of having FI (Menees et al., 2018). The variations in reported FI prevalence derived from data collection methods and two factors within definitions of FI: type of stool and frequency of FI episodes (Sharma et al., 2016).

Noticeable among various reports of FI prevalence is the association between older age and severity of FI. However, there seem to be an anomaly with oldest population group. As can be noted from Figure 1.3 (below), incontinence (both FI and UI) increases with age, up to 99 years and then declines (Melzer et al., 2015). The reason for this is probably because at that age metabolism declines, and generally oral dietary intake (food and fluid) also decreases. It may also be that those who survive to 100 years and above (centenarians) are less likely to have co-morbidities. Research evidence suggests lower comorbidities and treatment burden (as well as primary and hospital healthcare services compared with octogenarians (e.g., 80 to 89- year-olds) and nonagenarians (e.g., 90 to 99 -year- olds) (Clerencia-Sierra et al., 2020, Gellert et al., 2017).However, common among all age groups are the risk factors for cardiovascular disease (e.g., hypertension, dyslipidaemia, diabetes), cerebrovascular disease and dementia (Clerencia-Sierra et al., 2020).

There are some gender differences in how FI affects older people. For example, between the ages 95 years to 99 years, incontinence is reported to be almost 11.5% among females compared to about 8.5% among males of the same age (Figure 1.3).

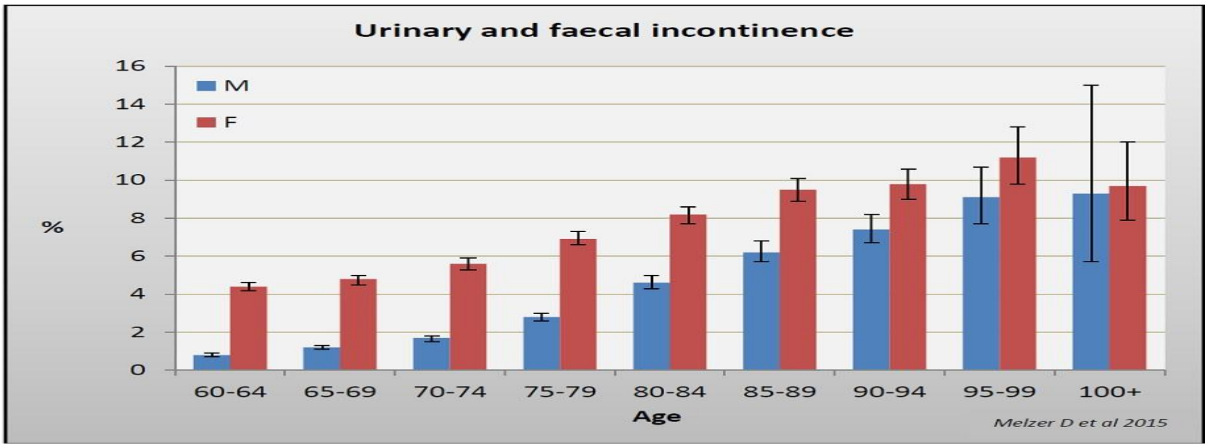

Figure 1.3: Prevalence of recorded incontinence symptoms and diagnoses in English general practice records in 2014 (Melzer et al. 2015)

The high prevalence of FI poses a significant management challenge to carers. This is partly due to the stigma attached to care work in general, and specifically to continence care. The next section highlights societal views about continence care as "dirty work", and the "emotional labour" that care staff employ when carrying out continence care.

1.7 'Dirty work' in the care home context: a "necessary evil"?

Dirty work is generally defined as tasks, occupations and/or roles that are likely to be perceived as disgusting or degrading (Ashforth and Kreiner, 1999), and are seen as physically, socially and/or morally tainted (Simpson and Simpson, 2018). Drawing on the early work of Everett Hughes (1962) in his text *Good People and Dirty Work*, a growing interest has been shown in recent years in forms of work that might come under this broad category (Galazka and O'Mahoney, 2021, Glerum, 2021, Ostaszkiewicz et al., 2016a, Simpson and Simpson, 2018). Within the care homes context, intimate care such as continence care, bathing and dressing of residents is carried out by care assistants (and occasionally by registered nurses) (Ostaszkiewicz et al., 2016a), with care managers often avoiding these messier routines. This type of work with older people holds a marginalised position in society and is often considered 'dirty work' (Dahle, 2005). Dant and Bowles (2003) argue that while there are social and moral elements involved in dirty work, there is also a materiality, based for example on bodily sensations of smell, touch, stickiness and slime.

The extent to which the work is considered dirty depends on the centrality and intensity of the dirtiness and its associated stigma (Kreiner et al., 2006). The societal perception that equates clean with good and dirt with bad leads to the perception of certain jobs as "dirty" (Douglas, 2002). The stigma attached to the work can be derived from any person or object possessing specific characteristics that society interprets as a threat to them (Crocker and Luhtanen, 1990). This leads to society outsourcing dirty yet necessary work to certain people (van Vlijmen, 2019) and distancing the mainstream from the dirt and from those who deal with it (Simpson et al., 2012). Invariably, workers engaged in dirty work face identity-threatening circumstances such as not being valued and considered unimportant (Bickmeier et al., 2014, Kreiner et al., 2006). Studies have found that adopting various coping strategies, workers engaged in dirty work maintain a positive identity even when facing the harsh realities of occupational stigma (Soral et al., 2022).

Four types of taint stigmatise dirty work and the workers engaged in such professions: (a) physical taint, when the tasks involve trash, bodily fluids, death, or other dangerous conditions (e.g., healthcare workers such as healthcare assistants, soldier, miner); (b) social taint, when the task involves contact with stigmatised communities (e.g., social worker, police detective); (c) moral taint, when the task requires a violation of ethical, social and religious norms (e.g., exotic dancers, psychics) (Ashforth and Kreiner, 1999); and (d) emotional taint, where the emotion associated with the work is considered to be dirty (e.g., border patrol) (Rivera, 2015). Dirty work is described as a "necessary evil" because while society may consider the work 'dirty', in most cases it is necessary to carry out the job (Soral et al., 2022). The jobs associated with physical and social taint are considered more necessary than the morally tainted occupations (Soral et al., 2022). For this reason, morally tainted dirty jobs are perceived as dirtier and pose serious identity threats compared to other dirty jobs (Soral et al., 2022). In this regard, continence care in the care home constitutes a physical taint for the care workers who engage in cleaning residents following incontinent episodes.

In a meta-synthesis of the resources used by the workers engaged in dirty work to cope with their occupational stigma, Prakriti Soral and colleagues (2022) found that adopting various coping strategies (with resources), workers engaged in dirty work maintain a positive identity even when facing the harsh realities of occupational stigma. Coping is a response to stressful events by regulating emotions, thoughts, physiology, and the environment (Aldwin, 2009, Compas et al., 2017). Soral and colleagues (2022) found several coping resources that care staff may find valuable when carrying out continence care. Among the coping resources relevant for carers in the care home settings included condition resources, constructive resources, social support resources, and key resources (Soral et al., 2022).

Defined as durable resources present in the social context (ten Brummelhuis and Bakker, 2012), condition resources are believed to be among the most popular resources to cope with occupational stigma. These resources are believed not only to help divert attention from the stigma but also help build a favourable occupational identity (Soral et al., 2022). Soral and colleagues (2022) found five types of condition resources: (1) learning on the job; (2) the nature of dirty work; (3) objective of the work; (4) occupational autonomy; and (5) occupational conditions and benefits. In the context of the carers working in care homes, learning on the job facilitates gaining new skills and helps the workers engage in a non-monotonous and relatively diverse work experiences (Sanders, 2010, Soral et al., 2022). In regard to the nature of dirty work, a study found that when homecare work was introduced with a rehabilitation concept, the workers no longer felt they were merely care workers; instead, they began to perceive themselves as coaches (Meldgaard Hansen, 2016). The objective of the work means that irrespective of the level of prestige of the dirty work, workers appreciate the “necessity shield” that their job is necessary and critical for society (Ashforth and Kreiner, 2014). By extension, the focus on ‘caring’ arguably makes workers perceive themselves as valuable to society, as was evident during the Covid-19 pandemic when such workers were called “heroes”. Defined as the amount of discretion the worker is expected to exercise in carrying out assigned work activities (Turner and Lawrence, 1965), occupational autonomy acts to maintain dignity among the workers (Hamilton et al., 2019). Workers maintain their autonomy by maintain physical and mental distance from the dirty tasks (Ostaszkiewicz et al., 2016a), and focus on completing the task (Gunby and Carline, 2020). Finally, occupational conditions and benefits suggest that refocusing on the non-stigmatised element of the jobs, such as financial benefit, time off, and flexible working hours, help workers have a positive outlook on their jobs (Bosmans et al., 2016, Soral et al., 2022).

Constructive resources such as knowledge, masculine/feminine traits, and mental resilience are individual personal resources that can help in affirming one's self-adequacy by perceiving that one is engaged in a worthwhile occupation and thus viewing oneself in a positive light (Harris et al., 2019a, Shigihara, 2018). For example, workers use personal autonomy and engage in framing their jobs as socially accepted careers. Social support resources, on the other hand, can be either an emotional or a practical aid given by others, enabling a perception that the person is loved and cared for by others (Taylor and Stanton, 2007). Thus, social support resources help individuals engage in self-affirmations to overcome the dissonance and regain their self-esteem. When workers are engaged in the work to serve clients, they develop close personal relationships with them (Ostaszkiewicz et al., 2016a, Soral et al., 2022). This sense of belonging helps in reducing servility and building a positive sense of self as "a person" rather than "a servant" (Sadl, 2014). Finally, Soral and colleagues (2022) found that self-efficacy and self-esteem were found to be the prominent key resources. The authors averred that contrary to common beliefs, dirty work involves technical tasks that require organizational skills, and that worker engaged in these jobs take pride in calling themselves authentic practitioners who possess the unique skills needed to conduct the job (Soral et al., 2022).

1.8 The concept of emotional labour in the care home settings: "caring against the odds"

Taken initially from a study of flight attendants (Hochschild, 1983), the concept of 'emotional labour' has been applied to nursing (Gray, 2009, Huynh et al., 2011, Huynh et al., 2008, Lopez, 2006, Ostaszkiewicz et al., 2016a). As part of her case for a "social theory of emotion," Hochschild argues that emotions are shaped not only by broad cultural and societal norms, but also are increasingly regulated by employers with an eye on the organizational interest (Hochschild, 1983). She coins the phrase emotional labour to describe the process by which workers are expected to manage their feelings in accordance with employer-defined rules and guidelines (Hochschild, 1983, Johnson, 2015, Wharton, 2009). In her work, Hochschild attempts to align privately felt emotions with normative expectations or to bring the outward expression of emotion in line with them. Hochschild

(1983) refers to the first process as “deep acting” and the second as “surface acting,” aiming to convey the fact that the first involves an attempt to change what is privately felt, while the second focuses on what is publicly displayed (Hochschild, 1983, Lightman and Kevins, 2019, Wharton, 2009).

Following the sociologist, Arlie Hochschild (1983) *The Managed Heart,* introduction of the term emotional labour, the term has been used to describe a worker’s endeavour to suppress his/her personal feeling in order to facilitate the public expression of emotion that make others feel that they are being cared for (Huynh et al., 2011, Newbold, 2004, Turner, 2007). The concept of emotional labour, in this thesis, will be extended to care homes care workers’ (healthcare assistants and nurses) internal self-regulation of emotions when caring for residents with dementia and faecal incontinence.

Emotional labour generally has three characteristics: it involves face-to-face or voice contact with the service users; it requires the employee producing an emotional state in others (e.g., a carer showing empathy, rather than feelings of disgust, when providing care to a resident following an incontinent episode); and it allows the employer to regulate a degree of control over the emotional activities of workers (e.g., through training and supervisions, staff handbooks, as well as an organisation’s vision statements) (Gray, 2009, Hochschild, 1983, Smith and Lorentzon, 2007). Management scholars (Chu, 2004, Grandey et al., 2005, Pugh et al., 2011) suggest that emotional labour is mainly dictated by organisational rules. In such instances, the organisation provides workers with scripted client interactions, thus controlling expressions of their interpersonal emotions (Grandey et al., 2007, Pugh et al., 2011). Nevertheless, the concept of emotional labour that has emerged from the nursing perspective, unlike other disciplines such as management and psychology that emphasise organisational outcomes, emphasises the health outcome of the patient (service user) and nurse (Huynh et al., 2008).

In a care home context, care workers’ management of emotion has often been seen as an important skill that has potential therapeutic value to both those cared for and the carers (Foster and Hawkins, 2005, Gray, 2009, Lightman and Kevins, 2019, Xue and Heffernan, 2021). The phrase ‘emotional labour’ seems well suited to care homes work, which involves face to face encounters between care workers and the care home residents. These face-to-face encounters in the care homes include legitimate touching, personal conversation and shared environment that are even less affected by technical operations performed in the airline work described by Hochschild (1983). Care workers in care homes face a unique set of challenges that include routine acts of intimate care that are usually done alone in the privacy of home. Within care homes, however, these everyday activities—bathing, toileting, dressing, and feeding—are transformed into labour to be carried out by low-paid healthcare assistants who often work under difficult conditions that prioritise the care homes' vision and national guidelines over the emotional aspects of the carers' duties (Rodriquez, 2011). For these reasons, care workers role in continence care may be described as caring against the odds.

Hochschild's (1983) theory of emotional labour, when applied to the care workers in the care homes, differentiates the ideal emotions and thoughts that care workers should feel and those that they actually experience but cannot express in practice (Huynh et al., 2008). In other words, care workers providing everyday care to residents in areas such as continence and dementia are expected to suppress their personal feelings over the care homes' defined priorities and guidelines. It has been found that some care home organisations achieve this by publications on their websites, such as vision statements and induction training (Johnson, 2015). Perhaps, this happens because given the history of institutional abuses in care home settings, managers in contemporary care homes spend much of their time and attention on maintaining regulatory compliance (Gittler, 2008). While such monitoring contributes to the well-being of current and future care home residents, it also generates untoward demands on the emotional lives of workers beyond what the management had intended (Rodriquez, 2011).

Nevertheless, this view seems contrary to a common assumption in the healthcare literature, which suggests that the quality of nursing care is, in part, achieved by means of nurses' emotional commitment to those in their care (Huynh et al., 2008). Likewise, both patients' complaints and wider public concern over poor quality care have been framed as a response to a lack of emotional sensitivity on the part of healthcare professionals (Fletcher, 2000, Francis, 2013). Furthermore, care homes are unique in the world of care work because they involve intimate interactions with residents for extended periods of time. Care home staff develop emotional attachments to the residents they provide care to, even as those emotions are constrained by the care home; the workers often say that the residents become ‘like family’ (Dodson and Zincavage, 2007, Rodriquez, 2011). Francesca Cancian (2000) avoids using Hochschild’s concept of emotional labour altogether, opting instead for an alternative notion of ‘emotional care’. Cancian suggests that it is possible to create rules and standards for emotional care of residents’ needs just as there are rules and standards for physical care needs of the residents (Cancian, 2000). However, it is not sufficiently clear how Cancian’s notion of organisational rules and standards for emotional care is different from Hochschild’s conception of organisational feeling rules for emotional labour (Lopez, 2006).

Care workers experience intense emotions at work that are fundamental and inseparable parts of human action in organisations (Eide, 2005, Huynh et al., 2008, Johnson, 2015). Experiencing emotions is considered essential for care workers to cope with morally difficult situations (e.g., residents refusing care following incontinence episodes) and to interact ethically and meaningfully with people in distress (e.g., supporting a resident who is at risk of self-harm due to underlying dementia (Badolamenti et al., 2017, Carers UK, 2022, Mjørud et al., 2017, Nogales-González et al., 2014, Wheatley et al., 2021).

In her case study, Johnson (2015) questioned whether sentiment has a more legitimate role to play in care work than in the work of flight attendants (Hochschild, 1983), and whether care workers can avoid the moral dissonances referred to by Hochschild (1983) and enjoy a properly recognised and valued commitment to emotional labour. Johnson (2015) found that care workers, encouraged by their employer (e.g., to display compassionate care at all times), naturalised their emotional labour, and that this had contradictory consequences. On the one hand, care workers undertake their caring duties because they feel they are positively impacting the lives of their service users and thus leaving them vulnerable to emotional over-involvement and client aggression. On the other, it allowed the care worker to defend the moral interests of those within her care and to see when those interests were in conflict with the economic motivations of her employer (Johnson, 2015).

England (2005), in her seminal article *'Emerging Theories of Care Work'*, outlines two frameworks: the Prisoner of Love framework, and the Commodification of Emotion framework. The Prisoner of Love framework emphasises that despite the explicit and implicit costs of working in a caring occupation, helping others has intrinsic benefits (England, 2005). According to the Prisoner of Love framework, care work relies on the altruistic motivations of (typically female) workers (Folbre, 2012) and is found, in many cases, to be uniquely rewarding (England, 2005, Lightman and Kevins, 2019). In her case study, Eleanor Johnson (2015) found that rather than portraying emotion as a weakness (Gray, 2009) to employees, the care home implied that workers who acted upon their 'natural', 'altruistic motivations' would find their work rewarding in its own right. Five of the six new recruits to her case study described their motivations to become carers in terms of how the role would allow them to express their philanthropic nature and realise their true self (Johnson, 2015). On the other hand, the Commodification of Emotion framework suggests that because caring occupations require 'deep acting' by workers, they force the workers to pretend that they care about their clients, which ultimately increases stress and work alienation (England, 2005, Lightman and Kevins, 2019).

Zapf (2002) proposed three strategies that the care workers might use for emotional management: automatic emotional regulation, surface acting, and deep acting. For the automatic emotional regulation, emotional work in this strategy is carried out automatically and is moderated by the level of social competence of the worker (Zapf, 2002). Surface acting involves management of the visible aspects of emotion, such as the facial expression, voice, and gesture, to be consistent with the display rules appropriate to that situation (Newbold, 2004, Zapf, 2002). Sometimes a worker may be expected to display emotions they do not actually feel, which is termed as 'emotional dissonance' (Zapf, 2002). The Deep acting strategy involves the worker not only displaying expressive behaviour consistent with the display rules, but also strives to regulate their inner feelings in order to become the role they are asked to display (Zapf, 2002). It is likely that this strategy would induce the feeling of being cared for and possibly reduce the level of emotional dissonance felt by the worker (Newbold, 2004). In one study, Tsukamoto and colleagues (2015) found that because care home workers try to provide-high quality care to residents, they must pay attention to their own attitude, which might be different from their feelings if they are undertaking emotional labour. The authors recommend facility managers recognise that emotional labour might affect general health and job satisfaction among care home care workers (Tsukamoto et al., 2015).

In the next section, the characteristics of a care home, its population (residents) and workforce (care staff) are highlighted. These pieces of information are important to enable development of an intervention that is context-dependent and tailored to the intervention beneficiaries as well as those that deliver the intervention.

1.9 Characteristics of the care home, its population and workforce

1.9.1 The care homes

Care homes play a vital role in public health infrastructure by providing accommodation, nursing care and/or personal support to vulnerable adults who are unable to live independently (Iliffe et al., 2015, Public Health Scotland, 2020). In the UK, there are marked differences in the care homes organisational size, ownership, funding sources, focus, education of the workforce and organisational culture (Glendinning et al., 2002). Many UK care homes are privately owned, and others are run by charities or councils. Some care homes are based in adapted housing, while others are based in large purpose-built communal centres. People whose care is paid for by a local authority or trust may go into a care home at a later stage than those who self-fund. Many care homes in the UK have 35 beds or fewer (Staley et al., 2017). This variability has implications, for example, for the way in which interventions to support continence care are understood and implemented (i.e., the presence or absence of on-site nurses, incontinence topic expertise in the workforce, and staffing).

Care homes are the main providers of long-term care for older people in the UK, and there are approximately three times as many beds in the care home sector as there are NHS hospital beds (DEMOS, 2014, Iliffe et al., 2015). However, care homes are plagued by challenges that make them a less attractive place to reside in later life. They are frequently understaffed and often struggle to keep up with the complexity of care needed by residents

(Boorsma et al., 2011). While a few care homes provide a feel of ‘normalisation’, the majority of them have been found to have a functional, institutional and clinical feel with ergonomics that are often uncomfortable and unsuitable for people with cognitive impairment (i.e. lacking practical signage), which can exacerbate confusion and anxiety among residents (Older People's Commission for Wales, 2014).

Normalisation here refers to the chance given to care home residents to live as close as possible to everyday life of a person not needing care (Vermeerbergen et al., 2017). This lack of normalisation in care homes can also be viewed from the perspective of an ‘institutional regime’ whereby, rather than addressing individuals’ care needs, care staff often carry out a task-based approach to delivering care (i.e. schedules, processes and checklists) (Older People's Commission for Wales, 2014).

Crucially, care homes are under public pressure to improve quality of life (QoL) and functional ability among care home residents (Older People's Commission for Wales, 2014). However, evidence suggests that the care home sector is less prioritised compared to acute NHS care by national government (Age UK, 2017, British Geriatrics Society (BGS), 2011, Enabling Research in Care Homes (ENRICH), 2017). It is important to emphasise that the health needs (including personal care such as continence care) of this subgroup of the population and the public demand for best quality care will likely increase amidst an aging UK population (ONS, 2016). Fortunately, this situation has begun to improve (National Institute for Health Research (NIHR), 2017). The NHS England’s enhanced health in care homes (EHCH) is a practical embodiment of the recognition that good health, health care and social care are mutually dependent and need to be approached together (Bayliss and Perks-Baker, 2016). Amongst others, the programme recognises that a multidisciplinary team support, including a range of health and social care services, enhanced primary care support into the care homes (e.g., regular visits and assessments by clinicians, rather than reactive interventions), and workforce development and information-sharing are core elements that can enable care homes and health services to work together effectively to enhance residents’ health (Bayliss and Perks-Baker, 2016). The EHCH focuses on proactive care that is centred on the needs of individual residents, as opposed to traditional reactive models of care delivery (National Health Services (NHS), 2020).

In the UK, it is important to emphasise that care homes are regulated by different inspection bodies: the Care Quality Commission (CQC) for England (CQC, 2022), Care Inspectorate Wales (CIW) for Wales (CIW, 2022), the Care Inspectorate for Scotland (Care Inspectorate, 2022), and the Regulation and Quality Improvement Authority (RQIA) for Northern Ireland (RQIA, 2022).

1.9.2 *The care home population*

To increase probability of success of an implementation strategy in a health and social care setting, it is vital to have relevant knowledge not only about the setting, but also knowledge about its residents (Blekken et al., 2016). Over 70% of the care home residents need professional care, such as assistance with activities of daily living, nursing care (e.g., medication, wound care) and housekeeping. They have multiple chronic diseases and associated disabilities (Boorsma et al., 2011).

In the UK, the population of care home residents has changed dramatically over the last ten years, to include many older people living with severe frailty and illness. There are an estimated 490,326 older people aged 65 years and above who are reportedly living in 17,598 CHs in the UK (Berg, 2021, Frederic, 2021). Of the current number of older people living in CHs, 418,710 of them are reported to reside in England, 24,178 of them reside in Wales, 35,630 reside in Scotland, and 11,808 of them reside in Northern Ireland (Audit Wales, 2021, Berg, 2021, Department of Health, 2020, Frederic, 2021). While the care home residents represent a minority of older people (which is currently about 11 million people aged 65 years and over) (Center for Aging Better, 2022), they are nevertheless integral to the long-term health care system and comprise of some of the most vulnerable people in our society (Barker et al., 2020, Gordon et al., 2014).

Almost all care home residents have three or more health conditions, and about one-third of them are living with advanced stage of a disease (Gordon et al., 2014). The average care home resident is said to have several comorbidities including Parkinson disease, severe stroke, functional dependency, and frailty (British Geriatric Society (BGS), 2016, Vetrano et al., 2018). More than half of the care home residents have dementia which may not always be medically diagnosed (Alzheimer's Society, 2013, Prince et al., 2014, Velayudhan et al., 2020). Dementia is an umbrella term that is used to describe a group of symptoms that are characterised by behavioural changes and loss of cognitive and social functioning (Dening, 2019). Although a dementia diagnosis has been described as a 'tick-box' exercise that is often done in primary care setting, early screening or testing have significant benefits for the patients and their family especially in supporting the management of other comorbidities of the person with dementia (Dening, 2019).

The late stages of dementia are usually described as 'advanced' or 'severe' dementia – although there is no straightforward clear definition of 'advanced dementia' (Social Care Institute for Excellence (SCIE), 2020). There are several measurement scales available in dementia care that help to establish how advanced dementia has progressed (Sheehan, 2012). Some of these measurement scales vary, for example the Clinical Dementia Rating Scale (O'Bryant et al., 2008), the Test Your Memory (TYM) (Hancock and Larner, 2011), the Mini-Mental State Examination (MMSE) (Hancock and Larner, 2011) or the Global Deterioration Scale (Reisberg et al., 1982, Reisberg et al., 2019). Therefore, one way to categorise 'advanced dementia' is to assess an individual's worsening level of engagement (both physically and cognitively) in activities of daily living such as eating, moving, communication, etc (Social Care Institute for Excellence (SCIE), 2020). The advanced stage of dementia impacts on several areas of human abilities: memory, communication, understanding, thinking, judgement, planning, learning and physical functioning (Gill et al., 2010, Mitchell, 2015, Social Care Institute for Excellence (SCIE), 2020). While some people with 'advanced dementia' may be unable to walk, stand up or to weight bear, others may move around a lot (sometimes walk for large amount of the day (Alzheimer's Society, 2022, Social Care Institute for Excellence (SCIE), 2020). This is often noticeable in care homes where more mobile residents with advanced dementia may seem to spend their whole day walking up and down the corridors and in and out of rooms (Campbell et al., 2020, Rapaport et al., 2018). Although some people living with advanced dementia may seem completely silent and unresponsive to communications, others with the same stage of dementia may talk a lot (although not in ways that are easily comprehensible) (Alzheimer's Society, 2022, Social Care Institute for Excellence (SCIE), 2020).

In the general population, research evidence suggests that there were an estimated 885,000 older people in the UK living with dementia in 2019, of whom 84.7% (748,000) lived in England, 7.5% (66,300 people) live in Scotland, 5.3% (46,800 people) live in Wales, and 2.5% (22,000 people) live in Northern Ireland (Wittenberg et al., 2019). Among the figure reported in 2019, 127,000 of them were reported as having mild dementia, 246,000 as having moderate dementia, and 511,000 had severe dementia (Wittenberg et al., 2019). Today, however, there are approximately 944,000 people with dementia in the UK (Alzheimer's Research UK, 2022). The increase in the prevalence rate and the number of older people living with dementia is said to be driven by the continued aging population (Wittenberg et al. 2019).

Meanwhile, it is believed that people living with dementia are more likely to experience incontinence (and/or difficulties using toilet facilities) than people of the same age without dementia (Alzheimer's Society, 2021a). For people living with the advanced stage of dementia, incontinence may develop because they are not able to properly process messages between the bladder and the bowel due to cognitive decline (Alzheimer's Society, 2021a). People living with advanced dementia may not recognise that they have a full bladder or bowel; they may be unable to react quickly enough to the sensation of needing to use the toilet, or even tell someone that they need to go to the toilet because of communication difficulties (Alzheimer's Society, 2021a). Unfortunately, carers (and health professionals in general) do not always recognise the needs of a person with dementia, and may tend to attribute the person’s behaviour to the dementia, with resultant diagnostic overshadowing (Dillane and Doody, 2019, Kerr et al., 2011).

Untreated depression is a major cause of morbidity in older people, particularly in those who live in care homes (Underwood et al., 2013). Up to 40% of care home residents meet criteria for significant depression on validated depression symptom scales (Krishnamoorthy et al., 2020). Meanwhile, treatment with antidepressants may not always be appropriate because of potential drug interactions and toxicity, which can lead to, for example, an increased risk of falls (van Poelgeest et al., 2021). In a large NIHR study that investigated whether exercise and increased general activity could reduce depression among care home residents, it was reported that nearly half of over 1000 residents recruited to the study were suffering from depression (Underwood et al., 2013).

Meanwhile, there is evidence that around 80% of people in care homes experience regular pain, caused by conditions like arthritis or pressure sores (Corbett et al., 2016). Besides causing great discomfort and distress, untreated pain limits movement and is a major cause of behavioural problems (Achterberg et al., 2020, Caroline Kreppen et al., 2022). Researchers in one study found pain management in people with dementia to be particularly difficult because these patients are often unable to describe their pain in words (Corbett et al., 2016). In such instances, care workers and relatives play important roles because they can often tell whether the person with dementia is in pain and whether any treatment is working. ‘Knowing the person’ becomes essential to providing the most suitable treatment and care (Corbett et al., 2016). There is evidence that having dementia and/or depression has correlation with severe pain among care home residents (Rajkumar et al., 2017).

Therefore, supporting care home residents to age well means managing these conditions successfully and dealing with new symptoms promptly to minimise the impact on their quality of life. For residents with two or more long-term health conditions, current policy and practice are focused on providing person-centred care, as described in NICE guidance (National Institute for Health and Care Excellence (NICE), 2016). The goal is to improve the individual’s quality of life by promoting shared decisions on treatment and care, based on what is important to each person. This care-tailoring approach means supporting individuals to make informed choices, weighing up the potential burdens of care – from multiple medications, multiple appointments, and unnecessary admission to hospital - against the likely benefits (NICE 2016).

Reports suggest an increase in the number of old and very old people in the UK and throughout the world, which challenges health and social care systems to provide effective and sustainable care to this group of the population (Vetrano et al., 2018). The noticeable change in the demography of the UK care home population has arisen probably because of a policy shift towards maintaining older people’s independence for as long as possible in their own homes. This appears likely from the NHS Community Care Act 1990 which came into effect in 1993 and set measures by which social care services are encouraged to promote care and support services for people in the community rather than in institutions (Department of Health and Social Care, 2022b). While there are advantages in supporting older people to live at home in terms of preserving dignity, reducing risks of infection, and ultimately cutting down healthcare expenditure, it arguably leads to admission to care homes of only the most vulnerable members of a society who are elderly, frail and with multiple health conditions.

Meanwhile, there is evidence that a number of older people that receive home care experience loneliness (Wilson et al., 2007). In the UK, a report suggests that approximately 32% (3.64 million) of older people aged 65 years and above live alone (Age UK, 2017). Research studies have found that loneliness is a risk factor for developing Alzheimer's Disease (Age UK, 2015, Courtin and Knapp, 2017, Wilson et al., 2007), and that loneliness can lead to premature death because it is as harmful as smoking 15 cigarettes a day (Holt-Lunstad et al., 2015). The often poorer health conditions of people admitted to care home coupled with unhelpful media coverage of poor standards of care in the care homes (Knapton, 2017) seems to impact on the status of the care home sector, making it the place of last resort for older people and their families (Owen et al., 2012).

The next section highlights the length of stay (from admission to death) of a care home resident. This information is important when planning intervention for this subgroup of the population.

1.10 Length of resident stay in a care home

The average care home resident is likely to have a life expectancy of 12-30 months (Moore et al., 2020, ONS, 2021) A study commissioned by BUPA (a private provider of care homes) that was conducted in the UK found that the median period from care home admission to death is 15 months (462 days) (Forder and Fernandez, 2011). After hospitals, care homes are the most likely place of death for people aged over 65 (Moore et al., 2020). Approximately 18% of older people in England die in care homes (Staley et al., 2017). This number is set to increase as the population ages and inappropriate admissions to hospital from care homes are reduced. Therefore, care homes play a significant role in end of life care provision and are only likely to expand this role in future (Staley et al., 2017).

As the population ages, the need for accessible, appropriate long-term care provision will become a global priority. Despite being reported as the least preferred place of death, older adults with dementia and multiple, complex conditions often die in long-term care facilities (LTCFs), although the proportion of deaths differs significantly between countries (Bone et al., 2018, Calanzani et al., 2014). In England and Wales, care homes are projected to become the most common place of death for older adults by 2040 (Bone et al., 2018).

A systematic review of factors associated with length of stay before death in care homes identified that shorter lengths of stay in the care home was associated with older age, being male, having a cancer diagnosis, shortness of breath, receipt of oxygen therapy, and residence in care homes providing nursing care (as opposed to social care) (Moore et al. 2019). In particular, the same review found stronger evidence for the association of poor physical functioning and shorter lengths of stay compared with cognitive functioning. The findings of the review were limited as no international studies using data comparable between countries were identified and few studies included characteristics related to the facility (Moore et al., 2020).

A study investigating resident, facility and country characteristics associated with length of stay in care homes [described as long-term care facilities] across six European countries found that the length of stay in care homes varied significantly between countries (Moore et al. 2020). The authors reported that the proportion of deaths within 1 year of admission was 42% (range 32%–63%). Older age at admission (HR=1.04; 95% CI 1.03 to 1.06), being married/in a civil partnership at time of death (HR=1.47; 95% CI 1.13 to 1.89), having cancer at time of death (HR=1.60; 95% CI 1.22 to 2.10) and admission from a hospital (HR=1.84; 95% CI 1.43 to 2.37) or another LTCF (HR=1.81; 95% CI 1.37 to 2.40) were associated with shorter lengths of stay across all countries (Moore et al., 2020). However, being female was associated with longer lengths of stay in care homes (HR=0.72, 95% CI 0.57 to 0.90) (Moore et al., 2020).

A previous study also found that being overweight (HR=0.79; 95% C.I. 0.64–0.97) and obesity (HR=0.64; 95% C.I. 0.48–0.87) was associated with lower mortality then normal weight (Vetrano et al., 2018). Similarly, the same study found that physical activity (HR=0.67; 95% C.I. 0.54–0.83), social activities (HR=0.63; 95% C.I. 0.51–0.78), influenza vaccination (HR=0.66; 95% C.I. 0.55–0.80) and pneumococcal vaccination (HR=0.76; 95% C.I. 0.63–0.93) were associated with lower mortality. Conversely, underweight (HR 1.28; 95% C.I. 1.03–1.60) and frequent family visits (HR 1.75; 95% C.I. 1.27–2.42) were found to have correlation with higher mortality (Vatrano et al. 2017). The utility of these research findings is that untangling which goals and priorities are the most meaningful health determinants of care home residents may result in the most beneficial interventions in this care settings. Additionally, understanding of the expected length of stay for older people admitted to a care home is important for estimating lifetime costs and the implications of reforming funding arrangements for social care needs (Moore et al., 2019).

The next section explores the characteristics of the workforce who provide care for older people living in care homes.

1.10.1 The care home workforce

The care home workforce is predominantly females who work either flexibly or part-time because they often have responsibilities looking after children and/or elderly parents, and most of them are paid close to or below the National Living Wage (Unison, 2015). Carers working in care homes who are not Registered Nurses (RNs) are described as Care Assistants, Healthcare Assistants (HCAs), Support Workers, or Nurse Aids (Bach et al., 2008, Kroezen et al., 2018, Nash and Fitzpatrick, 2015). Throughout this thesis, these terms will be used interchangeably to refer to care staff (other than RNs that have nationally recognised qualifications) who provide care to older people in care homes. Care Assistants are often stereotyped as not qualified to do anything else (although anecdotally several care home workers, particularly foreign workers, are either qualified nurses from their home countries, or graduates). Such misconception about the care home workforce makes it less attractive for jobseekers, thus leading to staffing problems. Many care homes rely on agency staff and foreigners, some of whom may not have had previous caring experience or do not understand cultural differences (Booth, 2020b).

In terms of qualified nurses (e.g., RNs) working in care homes, typically there is an average of 18 residents per registered nurse (RN) during the day, and 26 residents per RN at night (Royal College of Nursing (RCN), 2010). This contrasts with NHS hospital wards where a survey showed there are eight patients per RN during the day to eleven patients per RN at night (Ball et al., 2014). The workload, coupled with less career progression routes in care homes, probably make it the least attractive option for registered nurses. Meanwhile, it has been noted that recurrent short staffing can lead to poor quality of care and quality of life outcomes for people receiving care (Francis, 2013); it can lead to stress among staff, higher sickness absence, and increased staff turnover (RCN 2010).

Meanwhile, the care home workforce in the UK is regulated by codes of conducts: the Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England which governs the practice and professional expectations of care home staff (Department of Health, 2013), and the Nursing and Midwifery Council (NMC) Code of Conduct outlines the professional standards that nurses (Nursing and Midwifery Council (NMC), 2018). The workforce is also regulated by statute: the National Minimum Standards for Care Homes for Older People were introduced as a result of the Care Standards Act (2000) (UK Government, 2022a).

1.11 How UK Care Homes are funded

It is reported that care homes provide more beds than the NHS hospitals (Iliffe et al., 2015). In the UK, health care is free for older people, but social care services for older people are not free. There is a marked difference in social care funding across the four jurisdictions of the UK partly because of the dissonance between health and social care sectors. Most people must pay a considerable amount of money for their social care needs, including care home fees and personal care (Gordon et al., 2014). How much individuals pay is usually dependent on "means testing" – that is an individual's circumstances such as level of care needs, financial status, and geographical region. Funding may be either partially or totally paid for by a local authority (council) subject to the "means-tested" approach.

The UK care home sector remains fragmented as funding diminishes and public expectation of quality care increases. It is suggested that the most important issues affecting the long-term sustainability of care homes in the UK is its current model of funding (Cousins et al., 2016). It is perhaps helpful to put the care home funding problems into historical perspective. Back in 2008, the world witnessed the collapse of investment bank Lehman Brothers which was linked to Subprime mortgage problems that climaxed in 2007 in the USA. The situation was followed by massive bailouts by financial institutions to prevent potential collapse of the global financial system. Nonetheless, the crisis led to economic downturn globally. The Conservative and Liberal Democrat coalition government introduced austerity measures in 2010 to reduce the government budget deficit by reducing public spending. The austerity measures meant that local authorities' budgets were cut down by almost 50% (Rex and Campbell, 2022). This resulted in spending cuts on social care, resulting to a decline in fees the cash-strapped local authorities could pay towards residents' care.

Many care homes are struggling because of a decrease in the amount that councils pay towards care home residents. According to Laing and Buisson (2015), an average fee of £512 a week paid by councils in England results in a shortfall of £42 per resident. Another issue that also add strain to care homes funding is the rising costs of running a care home driven by an increase in the national living wage, which has also increased payroll costs. The impact of the latter variable is that care homes are likely to have insufficient resources to organise training courses for their staff, thus resulting to poor quality of care. The Care Quality Commission has reported that approximately 7% of care homes provide inadequate services to residents and about 18,000 of them require improvement (CQC 2016).

Southern Cross, then the largest independent provider of care homes in the UK collapsed in 2011, a situation that threatened homelessness for more than 30,000 care home residents (Cousin et al. 2016). The number of beds in UK care homes fell by 3,000 in 2015, the first decline in almost a decade (Laing and Buisson, 2014).

Meanwhile, with the current health and social care systems under tremendous financial pressure – amid market instability, rising levels of unmet needs (i.e. difficulties in carrying out essential activities of daily living (ADL)) and pressure on adequacy of care provision (Age UK, 2017) – a rise in cost of maintaining this subgroup of the population seems almost inevitable. The coronavirus (Covid-19) pandemic has also highlighted the limitations of a financial model which is reliant on earned income and therefore exposes councils (and by extension, service users) to high levels of risk. Currently, council leaders are warning of further spending cuts as Covid-19 leads to a drop in income (Rex and Campbell, 2022).

1.12 Overview of challenges facing care homes – in practice and for research

1.12.1 Care Home Practice in the UK

In the UK, despite the recognition of contributions made by the care home sector, the industry continues to face many challenges especially in terms of funding, staffing, and education and research problems (Cousins et al., 2016, Spilsbury et al., 2015). This section outlines some of the challenges (in addition to the ones outlined above) faced by the UK care home industry that need to be considered when developing evidence-based interventions for the sector.

It has been reported that nursing jobs within the care home sector are broadly defined (Cousins et al., 2016), and this may present some difficulties to nurses working within the care home sector. Care home nurses serve multifaceted roles including clinical roles, gatekeepers and advocates for residents especially in terms of access to medical and specialist services (i.e. diabetic, palliative care, infection control, tissue viability, speech and language therapist, etc.) and they ought to know how to promote dementia patients' well-being given the prevalence of people living with dementia in care homes (Cousins et al., 2016, Spilsbury et al., 2015). It is not surprising, therefore, that many care homes struggle to retain competent staff for long periods. Evidence suggest that lack of competence among staff can lead to poor outcomes for residents and it may also increase unnecessary referrals of residents to NHS services (Spilsbury et al., 2015).

The code of practice for nurses emphasises that nurses must put the interest of the people using or needing nursing services first; they must make patients' care and safety their paramount concern and ensure that the dignity of people in their care is preserved (Nursing and Midwifery Council (NMC), 2015). It further recognises that the delivery of safe and effective health care is subject to appropriate staffing (NMC 2016). However, with such a level of workload in the care homes, upholding the NMC code of practice is challenging.

Compounded by the care home workload, there is no national minimum requirement for staffing levels within either primary care settings (National Institute for Health and Care Excellence (NICE), 2014), community settings (Mitchell et al., 2017), or care homes in the UK, in comparison to Australia and the USA, where staffing levels in terms of nurse-to-patient ratio in care homes are being enacted into laws, championed by the Australian Nursing Association and the California Nursing Association respectively (Mitchell et al., 2017, Osborne, 2014). However, it must be acknowledged that within the UK, the Welsh Assembly Government has taken measures to ensure some standardisation in terms of nurse-patient ratios (Welsh Government (WG), 2017),although the current measure applies only to acute care settings. In the meantime, there remain inadequate staffing levels and skill mix in UK health and social care system, particularly in most care homes.

1.12.2 Research in care homes

Another challenge to the care home industry is that it is not a typical place for research (Bonell et al., 2018, Long et al., 2018). While a few care homes in the UK collaborate with universities for practice development, education and research, many larger care homes lack such facilities (Cousins et al., 2016). Historically, many care home residents, especially those living with dementia, had been under-represented in research (Bayliss and Perks-Baker, 2016). Many administrators of care homes may be reluctant to allow research to be conducted in their facilities. One reason for administrators' reluctance to support research in care homes is arguably the fact that care homes are prone to changes in management or ownership, with some managers on temporary contracts. Where a care home welcomes research activities, recruitment of residents into a study is often difficult and time consuming. This is attributable to the high prevalence of care home residents with visual and auditory impairments, as well as dementia, which present challenges to obtain valid informed consent from residents to participate in research. Considering the prevalence of dementia in people within the care homes, research in the setting is usually challenging because the issue of valid informed consent is intractably linked to ethical and legal frameworks (i.e. assessment of mental capacity as per the Mental Capacity Act 2005) (Royal College of Nursing (RCN), 2015). One would be tempted to exclude potential participants on grounds of 'lack of decisional capacity' but doing so is tantamount to introducing selection bias, thus compromising the generalisability of findings.

Similarly, it may often become necessary to obtain a declaration from the personal consultees or nominated consultees of potential participants due to their cognitive impairments. However, there is often a challenge in contacting some of those consultees, and sometimes a consultee may be reluctant to agree for the resident to participate in research (Department of Health (DH), 2008). Also, important to consider for research in care home setting is sample size calculation because there is a high probability of subject attrition due to hospitalisation or death. It is reported that on average the length of stay from admission to care home to death is 15 months (462 days) (Forder and Fernández, 2011). Hence, there is a high probability of attrition which threatens validity of the study.

Care homes are complex adaptive systems of interconnected sub-systems (Peryer et al., 2022) where people, tasks, technologies, the physical environment, and organisational culture interact (Brand et al., 2015, Pfadenhauer et al., 2017). Novel interventions in CHs can disrupt dynamic system relationships, which can lead to emergence of potentially undesirable outcomes not anticipated in the study design (Clark, 2013, Greenhalgh and Papoutsi, 2018, Moore et al., 2018). These unpredictable dynamic effects can pose complications for the validity of outcome measures (Bonell et al., 2006, Pfadenhauer et al., 2017). Many care home complex intervention studies have produced neutral or inconclusive findings (Kinderman et al., 2018, Moniz-Cook et al., 2017, Surr et al., 2020, Underwood et al., 2013). There is uncertainty about whether the neutral findings are attributable to interventions ineffectiveness, or as a consequence of the implementation process, or insensitive measurement tools (Peryer et al., 2022).

1.13 A fragmented system between UK Care Homes and the NHS

Care homes play a significant role in the UK health and social care sector because they provide accommodation, together with nursing or personal care to older people who do not require hospital-based interventions, who may be frail and/or with cognitive impairment (Public Health Scotland, 2020). This suggests increase in non-acute care provision amid the rising aging population with increasingly complex care needs (Care Quality Commission (CQC), 2017, Cousins et al., 2016). However, there is incoherent collaboration among care homes and the healthcare sectors, which has profound ramification for some care home residents (Carter, 2011, Iliffe et al., 2015). It has been acknowledged that the UK care home residents are often poorly served by existing healthcare arrangements (Gordon et al., 2014).

The current system provides numerous approaches to how healthcare and social care provisions are met for care home residents. There is no care home-specific healthcare speciality in the UK such as is available in the Netherlands and USA (Conroy et al., 2009). Instead, primary health care is usually provided, free at the point of contact, by the National Health Service (NHS) through 'general medical services' (GMS) delivered by general practitioners (GPs) and their teams, and community health services such as district nursing and physiotherapy (Gordon et al., 2014). In some areas, extra services are provided by GPs through 'local enhanced service agreements' (LES), although it is up to health commissioners whether they wish to offer such arrangements and up to GPs whether they wish to participate (Gordon et al., 2014).

UK care home residents are supported based on how care homes are linked to community services, care home specialist nurses, designated NHS hospital beds, and GPs. As a result of such a fragmented system, there exists unequitable access to NHS resources among care home residents, especially for those care homes that provide specialist expertise in the form of rehabilitation, long-term care or dementia services (Robbins et al., 2013). This dissonance was echoed by the 2010 CQC survey of Primary Care Trusts (now Clinical Commissioning Group) which found disparity in provision of NHS services to care homes (Carter, 2011, Iliffe et al., 2015). Another report published by the British Geriatric Society (2016) concluded that there was a need for the NHS to clarify its obligations to care homes.

It has been observed that the NHS does not address the needs of older people, their relatives or staff because of the ways problems are defined and services organised (Goodman et al., 2013). A study conducted across 6 UK care homes to explore healthcare delivery to residents concluded that healthcare in care homes was difficult because residents' needs are complex and unpredictable. The study found that there was a mismatch between healthcare requirements of residents and GP time; ambiguities around roles and responsibilities of health and social care staff; and there were predominantly reactive healthcare provisions (Robbins et al., 2013). This has been supported by a review which found 15 surveys of working arrangements between care homes and the NHS, of which 10 of the surveys focussed on specialist services and another 5 surveys focused on primary care (Iliffe et al., 2015). Among others, the authors reported variability in access to a large variety of health professionals and services, different patterns of GP services (some GPs providing regular reviews while others do as per referral), and multiple practices and GPs working with single care home (for example, 30 practices visiting one care home) (Iliffe et al., 2015).

These findings suggest real difficulties in addressing the healthcare and social needs of older people residing in care homes. The findings also demonstrate that there are differences between care homes and the healthcare sector, particularly regarding uncertainty about shared roles and responsibilities. A possible explanation for the incoherent system could be that health care commissioners (purchasers) and professionals consistently underestimate the skills care home staff require and challenges faced by the care homes sector, as commissioners do not routinely have care homes specific targets for outcomes (Goodman, 2016, Iliffe et al., 2015). This is contrary to empirical evidence which suggests that a targeted multicomponent intervention which encompasses local health services can improve outcomes for care home residents and reduces use of secondary care (Szczepura et al., 2008). Additionally, there is no uniform data sharing system between the care homes and the NHS, as often seen in other countries where a standardised data sharing platform such as InterRAI or nomenclature of the minimum data set (MDS) exist (Musa et al. 2020). Therefore, there is a need for complex intervention for bowel care (encompassing mixed methods with varying approaches) that take accounts of a complex setting such as care homes which with rapid staff turnover of staff.

The overall research questions for this study are: (1) is it feasible to develop a faecal incontinence care intervention for older people aged 65 years and above living with dementia in care homes? (2) can the intervention lead to a reduction in frequency of faecal incontinence episodes among the care home residents? A detailed overarching research questions are contained in Chapter 4.

1.14 Chapter Summary

Chapter one sets out what FI is and lays out the operational definition of FI which will be used throughout in this thesis. It outlines how FI impacts the lives of older people in general, and specifically those living in care homes. It highlighted the impact of the condition not only on the older people, but also their relatives and the caregivers. The chapter shows the multifactorial underlying causes of FI, its prevalence among older people residing in care homes and the community. The chapter then explained the emotional labour the caregivers are required to employ when providing continence care. The characteristics of a care home and its residents and workforce is explored. Several challenges to expect within the care home sectors are also explored. Most importantly, the chapter highlighted the gaps in the literature relevant to this thesis (e.g., unknown prevalence and modifiable risk factors of FI among older people in the care home, and the lack of evidence-based intervention to prevent and/or reduce FI among older people living in care homes).

1.15 Organisation of the thesis

This thesis is divided into four parts. Part-1 consists of three chapters, which set out the knowledge basis about the research topic and encompasses what is already known and the gaps in the literature (Chapter 1), and how those gaps in the literature are addressed (Chapters 2 and 3 respectively). It contains findings from two systematic literature reviews, one on the prevalence, incidence, and correlates of FI (Chapter 2; PhD Paper-1) and the other on interventions for managing FI (Chapter 3; PhD Paper-2 [submitted]). The two systematic reviews have been peered reviewed and one has been published in a high impact scientific journal. Part-2 consists of three chapters (Chapters 4, 5 and 6) that set out the methodological structure and theoretical contexts for the thesis. Part-2 also sets out to test the theories using realist evaluation approaches. Part-3 of the thesis contains two chapters (Chapters 7 and 8): Chapter 7 collates the evidence from Chapters 2 and 3, in conjunction with evidence from Chapter 6 to develop an intervention for bowel care; Chapter 8 presents the feasibility study. Finally, Part-4 contains one chapter (Chapter 9), which evaluates the study and provides recommendations for future research and practice.

Chapter 2: The prevalence, incidence, and correlates of faecal incontinence among older people residing in Care Homes: A Systematic Review

Chapter 1 critically evaluated current knowledge concerning faecal incontinence (FI) and identified the lack of knowledge on the true burden of FI among older people living in care homes. To address that gap in the literature, a systematic review was undertaken to determine the prevalence, incidence, and correlates of FI among older people living in care homes. The systematic review has been published in a peer-reviewed journal and has already received 30 citations (Musa et al. 2019; PhD Paper 1).

The next section presents a description and justification for the methods utilised for the systematic review (Musa et al. 2019). A statement of contribution of the PhD student to this review paper appears on page 54 of this thesis. Supplementary materials in the published review paper have been relabelled as “PhD Paper 1” at the end of the thesis (Appendices 1-6) for better presentation.

2.1 Justification for databases searched

The search strategy was carried out in two steps:

(A) A search of Medline and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) to identify relevant abstracts on the prevalence or incidence of faecal incontinence, or double incontinence among care home residents aged 60 years and above. Further electronic searches were made via PROSPERO and the Cochrane library. The search included all published articles from inception to 30th November 2017. Example of the search strategy carried out on Medline is shown in Appendix 2: PhD Paper 1 Supplementary Table S2.

(B) A review of the full texts of all eligible articles, taking into consideration predefined eligibility criteria (Appendix 3: PhD Paper 1 Supplementary Figure S3), was carried out. To supplement electronic database searches, bibliographical mining and forward citation searching were used to identify relevant articles.

The rationale for using multiple databases and hand-searching of references is that investigators searching for relevant references for a systematic review are generally advised to do so to enable them adequately identify all literature related to the topic of interest (Beyer and Wright, 2013, Levay et al., 2015, Salvador-Oliván et al., 2021). There is a plethora of research studies that have been carried out to investigate the added value of multiple databases on different topics (Cooper et al., 2018, Hartling et al., 2016, Lorenzetti et al., 2014, Wright et al., 2015). The question of which databases are necessary to retrieve all relevant references for a systematic review remains unanswered (Bramer et al., 2017).

2.2 Justification for search terms

The initial search was made via Medline to identify relevant literature relating to epidemiology of FI among care homes residents. Key words searched included: “prevalence” OR “epidemiology” OR “incidence” AND “faecal incontinence” OR “faecal incontinence” AND “care homes” OR “nursing homes” OR “residential homes” OR “aged care facilities” OR “skilled nursing facilities”. The use of the Boolean operators helped to refine the literature search.

These search terms were identified during the background reading in Chapter 1. It is recommended for researchers to search for each identified search term individually, then use the correct Boolean operators (AND, OR, NOT) to combine the terms because it will help prevent any human errors; it also allows investigators to see which search terms add value to the search and if a particular search term produces too many irrelevant results (Bethel et al., 2021, Bramer et al., 2018, Cooper et al., 2018).

2.3 Eligibility of studies

The eligibility criteria are presented in Appendix 3: PhD Paper 1 Supplementary Table S3.

2.3.1 Inclusion criteria

- Studies on incontinence, where prevalence data on FI is available.
- Studies on incontinence, where in absence of FI only data, there is available data on double incontinence (DI).

- Studies relating to older people in care homes (NH and RH) setting, or where care home setting data are extractable.
- Participants' age ≥ 60 years, or participants' mean age ≥ 65 years.
- Peer reviewed, scientific journals.
- Studies published in English language.

2.3.2 Exclusion criteria

- Studies solely on prevalence of UI, or where FI and/or DI data cannot be obtained.
- Population based studies, where focus is not care home residents.
- Participants' age < 60 years, and/or mean age of participants < 65 years.
- Publications in languages other than English, with no English version available.
- Abstracts only with no full-text publication.

2.4 Rationale for eligibility criteria

Data on prevalence of FI were collected regardless of the explicit definition of FI. This is because the literature heighted no consensus definition of FI. Double incontinence (DI), the experience of both faecal incontinence and urinary incontinence, was considered as an eligible criterion because evidence suggests that many patients who are faecally incontinent are also doubly incontinent (Blekken et al., 2015a, Bliss et al., 2010, Norton et al., 2010, Saga et al., 2013). Therefore, excluding residents with DI (where there was no mention of isolated FI) would lead to ascertainment bias (i.e., underestimation of the prevalence of FI). Additionally, as this systematic review focused on residents within the care home setting, data from other settings such as patients in hospitals, or home dwellers were excluded because their inclusion would have led to misleading conclusions since evidence suggests that the model of care varies contextually across different settings. For the same reason, population-based studies which were not care home specific were not considered due to their inherent propensity to introduce "ecological fallacy" (e.g., when inferences about the characteristics or behaviours of individuals are derived from inferences about the group to which the individuals belong) (Idrovo, 2011, Walker, 2021).

The age limit of 60 years and above was selected for this systematic review to enable collection and comparison of relevant data since the definition of the term 'older people' varies globally. In many countries, this term refers to pensionable age. Whereas in many developing countries, the term refers to age above 60, in most developed countries the same term may refer to the age 65 years and above.

Studies published in languages other than English were not included in this systematic review. It was intended to exclude such studies only after the authors of non-English publications were contacted to get data in English but there was no reply. However, the search did not identify any non-English publication on this topic.

2.5 Summary and conclusions

Prevalence is confirmed as high and there are correlates of FI which are potentially amendable to intervention such as reduced mobility, laxative use, and altered stool consistency (e.g., constipation or diarrhea). However, little is known about what evidence-base interventions help to reduce FI among care home residents, most of whom have dementia.

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Review Article

The Prevalence, Incidence, and Correlates of Fecal Incontinence Among Older People Residing in Care Homes: A Systematic Review

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abstract

Keywords:
Fecal incontinence
prevalence
incidence
older people
care homes

Objective: Older people resident in care homes often rely on staff for support relating to their activities of daily living, including intimate care such as continence care. Managing fecal incontinence can be challenging for both residents and care staff. We conducted this review to describe the prevalence, incidence, and correlates of fecal incontinence among care home residents.

Design: Systematic literature review.

Setting and participants: older care home residents (both nursing and residential care) aged 60 years and older.

Measures: We defined double incontinence as the presence of fecal plus urinary incontinence, isolated fecal incontinence as fecal incontinence with no urinary incontinence, and all fecal incontinence as anyone with fecal incontinence (whether isolated or double). The CINAHL and MEDLINE databases were searched up to December 31, 2017, to retrieve all studies reporting the prevalence and/or incidence and correlates of fecal incontinence.

Results: We identified 278 citations after removing duplicates, and 23 articles met the inclusion criteria. There were 12 high-quality studies, 5 medium-quality studies, and 6 low-quality studies. The medians for prevalence (as reported by the studies) of isolated fecal incontinence, double incontinence, and all fecal incontinence were 3.5% [interquartile range (IQR) = 2.8%], 47.1% (IQR = 32.1%), and 42.8% (IQR = 21.1%), respectively. The most frequently reported correlates of fecal incontinence were cognitive impairment, limited functional capacity, urinary incontinence, reduced mobility, advanced age, and diarrhea.

Conclusions/Implications: Fecal incontinence is prevalent among older people living in care homes. Correlates included impaired ability to undertake activities of daily living, reduced mobility, laxative use, and altered stool consistency (e.g., constipation or diarrhea) which are potentially amenable to interventions to improve fecal incontinence.

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Previous reviews on the prevalence of fecal incontinence (FI) have concentrated on community dwellers.[1,2] To facilitate planning and provision of quality continence care in care homes[3] (a collective term for nursing or residential care setting, or nursing facilities), there is a need to understand the prevalence, incidence, and correlates of FI within care homes.

FI is the incapacity to appropriately control bowel movements, resulting in uncontrolled or involuntary leakage of feces that is a social or hygiene problem.[4e6] The commonly described types of fecal incontinence include urge incontinence (FI due to inability to reach to the toilet in time despite active attempts to avoid defecation), passive incontinence (involuntary loss of feces without awareness), and fecal seepage (leakage of stool after normal bowel movement, usually presenting as staining of underclothes).[7] FI can also be described as "functional" where the underlying problem is an inability to access an appropriate place to defecate or to clean effectively after defecation, rather than physiological inability to retain feces.[2] Research in FI among older people living in care homes has not been reported in terms of physiology but is instead based on stool consistency and/or frequency.[8e10]

FI is an under-reported but debilitating health problem that affects people of all ages,[11] and particularly older people living with dementia.[12,13] However, FI is not an inevitable consequence of old age or dementia alone,[2] but has multiple underlying factors,[14] some of which can be identified and treated.[15] In the older person, FI may be the consequence of age-related anorectal deficits such as reduced anal sphincter pressure;[16] it also may be underpinned by cognitive impairment,[17,18] length of nursing home stay,[10,19] diarrhea,[20] constipation,[10,17] or effects of polypharmacy.[21] When a cure is not achievable, incontinence management can produce "social continence" (incontinence well managed so that it is not socially evident), thus alleviating embarrassment and preserving the dignity of a person.[15]

An estimated 50% of older people living in care homes experience FI, compared with 18% of the general population.[19,22] FI may result in low self-esteem, stigmatisation,[3] and feeling of social isolation,[23] and in some cases it predicts mortality.[24,25] Generally, people are embarrassed to discuss their experience of FI with health care professionals or even with friends and family, as it can be seen as a "taboo within stigma"[26]; this is also the case in care homes.[27,28] Health care workers do not routinely broach the topic with care home residents,[5,6] perhaps because of attitudes of "therapeutic nihilism" (the belief that nothing can be done to help).[26] In a care home, where the majority of residents live with dementia, this nihilism can mean that residents are not assessed to find out why they are incontinent, and incontinence pads are used routinely.[2] Without any concerted effort to address FI, the dignity and quality of life of older people living in care homes will be compromised given that they are mostly older, frail, and have multiple health conditions compared to the general population.[29]

This review aimed to describe the prevalence, incidence, and correlates of FI among older people living in care homes. To the authors' knowledge, no similar review on this topic has been conducted. The following research questions are addressed: (1) What is the prevalence and incidence of FI among older people living in care homes? and (2) What are the correlates of FI in older people living in care homes?

Methods

Design

A systematic review of studies was conducted. The review followed the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) statement as a guide[30] and was designed to capture studies reporting prevalence, incidence, and correlates of FI (Appendix 1: Supplementary Table S1). The protocol of this review was registered with PROSPERO (number CRD42018082596), on February 14, 2018.

Search Strategy

Searches were made via MEDLINE and CINAHL (Cumulative Index to Nursing and Allied Health Literature) from inception to December 31, 2017. PROSPERO and the Cochrane Collaboration databases were also searched for relevant systematic reviews. Electronic searches were supplemented with hand-searching of reference sections from studies retrieved via databases.

Key search terms included prevalence, epidemiology, incidence, fecal/fecal, incontinence, care homes, nursing homes, residential homes, aged care facilities, and skilled nursing facilities. Considering the inconsistent use of the terms fecal incontinence and anal incontinence, we included anal incontinence to capture all relevant studies. We used medical subject heading (MeSH) themes and Boolean operators (and/ or) to refine searches to retrieve references specific to older people living in care homes (Appendix 2: Supplementary Table S2 shows an example of the search strategy).

Study Selection and Eligibility Criteria

None of the retrieved articles reported outcomes based on the etiology or mechanism of FI. No study differentiated soiling/passive FI from urge FI or functional FI, nor was volume (and often even frequency) addressed. Therefore, we considered data reported as isolated FI [FI without concomitant urinary incontinence (UI)][31,32] and double or dual FI (the occurrence of FI along with UI).[10,18] Where the authors did not differentiate isolated FI from double FI, we conceptualized the data to represent all FI (i.e., whether isolated FI or double FI). Inclusion of studies in this review followed a priori criteria (Appendix 3: Supplementary Table S3).

Data Extraction and Analysis

A standardized data extraction sheet was used to obtain study population characteristics, and diagnostic criteria used to define the outcome of interest (prevalence or incidence rate of FI) and factors associated with outcome measures (with crude or adjusted outcome variables as reported). Three investigators (M.K.M., S.S., and L.E.B.) independently extracted the data, and the results were discussed with C.N. as arbitrator. Any disagreements were resolved through reexamination and discussion of the study until consensus was reached.

Due to high variability across studies in methodological, clinical, and statistical differences, a decision to carry out a narrative synthesis of evidence instead of pooling data for a meta-analysis was made. We summarized the prevalence data as medians and interquartile ranges (IQR) because of the variability among reported FI frequency.

Methodological Quality of Identified Studies

The Joanna Briggs Institute (JBI) Checklist for prevalence studies was used, with 2 further questions from the JBI Checklist for Analytical Cross-Sectional Studies (questions 3 and 6) added to assess the correlational aspects of the studies. Two authors (M.K.M., S.S., or L.E.B.) independently assessed each study and then met with a fourth author (C.N.) to determine ranking as low, medium, or high quality (Appendix 4: Supplementary Table S4). All studies were qualitatively assessed, and where we were very certain taking into consideration risk of bias, a high quality was scored; where our confidence was very limited, a low quality was scored. We based our decisions on elements of the GRADE (Grading of Recommendations Assessment, Development and Evaluation) criteria.[33] There were 12 high-quality, 5 medium-quality, and 6 low-quality studies (Appendix 5: Supplementary Figure S1 shows methodological quality assessment of included studies).

Results

After the removal of duplicates, the searches yielded 241 citations, of which 202 were not considered relevant to the review question following screening of the title and abstract. The remaining 39 articles were read in full and assessed for eligibility. Sixteen articles were excluded: 5 were unavailable in English, 6 were not specific to care home residents, 3 were not related to the outcome of interest, and 2 care home data could not be extracted. Twenty-three studies met inclusion criteria for this review (Appendix 6: Supplementary Figure S2 shows the PRISMA Flow Chart).

Table 1

Summary of Prevalence Data

Year, Study	% Isolated FI (iFI)	% Double Incontinence (DI)	% All FI (iFI þ DI)	Definition of Frequency of FI	Data Collection Tool
Capewell et al, 1986	d	d	26	Once per week	Questionnaires completed by nurse in charge and interview with the same nursing staff
Tobin and Brocklehurst, 1986	d	d	10.3	At least once weekly	Interviews (residents and staff), and medical records
Burgio et al, 1988	3	75	78	Not stated	Interviews (nursing assistants) and medical records
Kinnunen, 1991	d	d	15	Not stated	Questionnaires and interviews (residents) by staff nurses
Peet et al, 1995	d	d	10.50	1 episode per week	Questionnaires
Johanson et al, 1997	d	d	46	Leakage of stool or soiling	Questionnaires completed by residents
Nelson et al, 1998	d	d	47	Usually, frequently	MDS data by trained professionals
Chiang et al, 2000	6	54	60	Not stated	MDS and medical records
Rodriguez et al, 2007	4	31	35	Not stated	Questionnaires completed by care home managers/senior staff
Harrington et al, 2008	d	d	43.10	More often than once a week	OSCAR data
Aslan et al, 2009	d	d	10.50	Once in 4 wk	Interviews of residents by RNs
Bliss et al, 2013	d	d	-	Not stated	MDS 2 and questionnaires
Saga et al, 2013, 2015	2.60	40.20	42.80	A few times a month	Questionnaires completed by RNs
Mandl et al, 2015	1	69.20	70.20	Any involuntary loss	Questionnaires completed by trained nurses
Blekken et al, 2016	d	d	42.10	Loss of liquid or solid stool	interRAI LTCF and St Mark incontinence score completed by RNs
Ihnat et al, 2016	d	d	57.10	Several times a week	Medical records and interviews of residents by nursing students
Jerez-Roig et al, 2016	d	d	42.70	Loss of liquid or solid stool	MDS 3 and medical records
Carryer et al, 2017	26	23.20	49.60	3-4 times a month	Questionnaires completed by RNs and care providers

Median of studies reporting prevalence	3.50	47.10	42.80
Interquartile range	2.80	32.10	21.10

LTC, long-term care; MDS, Minimum Data Set; OSCAR, Online Survey, Certification, and Reporting; RNs, registered nurses. The dash (d) indicates no data provided.

Description of Studies

There were 14 cross-sectional studies,[4,10,11,19,27,32,34e42] 4 cohort studies,[18,24,43,44] 2 surveys,[29,45] a quasi-randomized controlled trial[46] (from which we extracted baseline cross-sectional data only), a case-control study,[41] and a retrospective chart review.[47] One cross-sectional study was reported twice, in 2013 and 2015[10,48]; only the 2015 report is included in this review. The 23 studies come from diverse geographical locations and included sample sizes ranging from 82[46] to 1,526,066[36] care home residents (Appendix 1: Supplementary Table S1).

No standard definition of FI was applied across the studies. Some of the studies clearly defined FI but did so with differences of frequency by which fecal leakage constitutes FI: once a week,[29,35] several times a week,[19] few times a month,[10] or simply 1 involuntary leakage of feces[24] (Table 1). Other studies did not provide an operational definition for FI.[4,34,42,44] No study reported outcomes based on etiology or mechanism of FI, such as urge FI, passive FI, or post defecation seepage. There was a marked variation in data collection tools and the outcome measures differed: interRAI,[27] Cleveland Clinic Incontinence Score,[19] study-specific questionnaires,[10,42] interviews,[34] medical records,[24] and Minimum Data Set (MDS) records.[18,37,43,44,47] Findings from the included studies are presented under 3 subheadings in this review: prevalence of FI, incidence of FI, and correlates of FI.

Prevalence of FI

A summary of FI prevalence found in older people living in care homes is given in Table 1. Isolated FI interquartile ranged from 2.7% to 5.5% (median = 3.5%), double FI interquartile ranged from 33.3% to 65.4% (median = 47.1%), and all FI interquartile ranged from 28.5% to 49.6% (median = 42.8%). Older people living in care homes experience more double FI compared to isolated FI. The apparent anomaly of the median for double FI being less than all FI is because some studies did not report isolated and double FI separately, and mostly these studies reported lower rates of FI than those that did report separately (Table 1). No study categorized FI in terms of etiology.

From Table 1, it can be observed that older studies generally reported a lower prevalence of FI[39,45,46] compared with more recent studies.[11,19,32] It can be observed also from the table that more than 40% of residents were reported to have FI in studies reported after 2015.

Incidence of FI

Of the 23 studies reviewed, 5 studies analyzed incidence of new FI over time among care home residents.[18,24,41,43,44] In 1 of the studies conducted in 13 geriatric institutions in France to evaluate the incidence, identify the risk factors, and to assess the prognosis of older institutionalized patients aged 60 years and older who developed FI, it was reported that 20% (n = 234) of the participants (n = 1186) recruited without any history of FI and followed over 10 months developed new FI.[24] The authors reported 5 factors that were associated with increased risk of developing FI: UI [risk ratio (RR) = 2.0, 95% confidence interval (CI) = 1.5-2.6; P < .001], neurologic disease (RR = 1.9, 95%; CI: 1.0-3.4; P =.04), poor mobility (RR = 1.7, 95%; CI: 1.2-2.4; P <.001), age >70 years (RR = 1.7, 95% CI: 1.0-2.8; P = 0.04), and a Mini-Mental Status Examination score <15 (RR = 1.4, 95% CI: 1.1-1.9; P < .01).[24] They also reported that long-lasting (8 or more days') or permanent FI was associated with increased mortality.[24] Of the 234 patients who developed FI, 16% died during the study compared with 6.7% of those who were continent of feces throughout.[24]

However, the study did not find correlation between FI and age greater than 80 years, gender, medication use, or history of psychiatric disorder.[24] The study found a protective factor for developing FI in patients who had lived in the same institution for at least 5 years (RR = 0.6, 95%; CI: 0.4-0.8; P < .001).[24] This study seemed consistent with an earlier study that found that 23% of residents with FI compared with 11.9% of those without FI died at the 6-month follow-up.[41]

Table 2

Potentially Modifiable and Nonmodifiable Correlates

Author and Year of Publication	Bliss 2013	Bliss 2017	Blekken 2016	Ihnat 2016	Jerez 2015	Saga 2015	Aslan 2009	Nelson 2005	Chiang 2000	Chassagne 1999	Nelson 1998	Johanson 1997
ADL	Yes		Yes		Yes		Yes				Yes	
Diarrhea			Yes			Yes		No			Yes	Yes
UI	Yes		Yes		Yes		Yes	Yes		Yes	Yes	
Constipation						Yes		No			Yes	No
Mobility					Yes	Yes		No	Yes	Yes		
Laxatives			Yes		Yes					Yes		Yes
Depression			No			No		No	No		No	
Diabetes						No		No	No		No	
Older age	Yes		No	No	No	No		Yes		No	Yes	65*
Dementia	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gender			No	No	No	No	F$	No		No	M$	M$
Stroke					No	No	Yes	No			No	
Race/ethnicity	Yes	No						Yes				

Yes: statistically significant correlate; No: not statistically significant; blank spaces: not measured; F$ = females only; M$ = males only.

*Mean protective factor.

In Wisconsin, residents from 181 skilled nursing facilities found to be continent to both stool and urine in 1992 (n = 3850) were reassessed 1 year later to determine development of FI or UI.[43] The authors reported that 14.7% of the residents (n = 567) developed new FI, and an additional 12.4% (n = 479) developed double FI, so 27.1% presented with new FI in total over the year. Positive associations with the development of FI were dementia, advanced age, and nonwhite race, but the strongest correlates were impairment in activities of daily living (ADL) [odds ratio (OR) 3.1, 95% CI 2.6-3.8] and use of patient restraints.[43]

Adults aged 65 years and older who were free of double FI as per their Minimum Data Set (MDS) record when admitted to a care home were reported to have developed double FI, and did so sooner if they had UI, more severe limitations in ADL, greater severity of cognitive impairment, or more comorbidities, or if they were older.[18] The study also found a correlation between developing double FI and lower quality of care among care home residents.[18]

Correlates of FI

The most frequently reported correlates are dementia or cognitive impairment, functional incapacity or reduced ADL, UI, reduced mobility, advanced age, use of laxatives, and diarrhea (Table 2). Four studies showed that stroke is not correlated with FI. No study indicated what kind of dementia was present, and how dementia specifically affected continence. Other reported correlates include constipation, race (ethnicity), diabetes, depression, and length of stay in a care home.

Impaired ability to conduct ADL

Impaired ability to conduct ADL was reported as a significant correlate to risk of FI in 5 studies (Table 2). Impairment in components of ADL has been reported to be associated with poorer quality of life (QoL),[49] increased health care costs,[50] increased morbidity,[10] and mortality,[49] and as predictive of future dementia.[50,51] However, 1 study found that impairment in a component of ADL (inability to transfer between bed and chair) was a protective factor for not having FI (OR = 0.49, 95% CI 0.26-0.91; P <.001).[48] This counterintuitive finding is possibly explained by staff giving more assistance in bowel care to immobile residents compared to residents who were mobile.

Reduced mobility/Locomotion

Reduced mobility/locomotion as a component of ADL was independently analyzed and found to be associated with risk of FI. However, a cross-sectional study of nursing home residents (n = 359) in the United States found that locomotion was not associated with either isolated FI or double FI.[43] Another study conducted across 10 nursing home units (n = 261) in Norway found locomotion for more than 5 m as a protective factor for reporting FI (OR = 0.20, 95% CI 0.12-0.35; P < .001).[27]

UI

UI is a comorbid condition rather than a risk factor.[40] In this review, UI was 1 of the most frequently reported potentially modifiable correlates of FI. In 1 study, a multivariate logistic regression showed that compared with those without UI, the risk of FI increased 2-fold among those with UI (OR = 2.24; P < .001).

Laxatives

Laxatives used to treat or manage constipation varied, and included lactulose, Senna, suppository, or enemas. In this review, all such medications were considered as laxatives. Four studies found the use of laxatives to be associated with FI (Table 2).

Stool consistency

Constipation and diarrhea were both found to be independently associated with risk of FI. The term constipation in this review also includes data on fecal impaction (an immobile bulk of feces in the rectum) and fecal loading (a large volume of stool of any consistency found in the rectum) because both of the latter can cause the former (i.e., infrequent or difficulty of passing stool). The term diarrhea was considered synonymous to loose stool.

Depression and diabetes

Depression and diabetes were both found to be not statistically significantly associated with risk of FI. Six studies found depression to be a non-significant correlate of FI.[10,27,35,40,43,47]

Diabetes was also found to be non-significantly associated with risk of FI in 4 studies.[10,40,43,47]

Dementia

Dementia was the most consistent correlate of FI (Table 2). Cognitive impairment among residents with FI is reported as ranging from 54%[35] to 87%.[17] However, a cohort study conducted in France found that psychiatric disorder (which probably included dementia) was not correlated with FI.[24]

Advanced age

Advanced age was reported as a risk factor that is associated with FI among older people in 4 studies. One of the studies reported that the age 65 years or lower was a protective factor for FI.[38] Five other studies reported that age was not statistically significantly correlated with FI.[10,19,24,27,37]

Gender differences

Gender differences in FI were not statistically significantly associated in 6 studies (Table 2). However, 1 study found a correlation between female gender and risk of FI.[34] Two studies found male gender as significantly correlated with FI.[38,40]

Race or ethnicity

Race or ethnicity was found to be associated with development of FI in 2 studies.[4,43] In 1 study, isolated FI was 14% in blacks, 13% in Hispanics, 10% in American Indians, 9% in Asians, and 9% in whites; double FI was 46% in Asians, 44% in blacks, 36% Hispanics, 27% American Indians, and 27% in whites.[4] This study supports an earlier study that also found nonwhite race to be positively correlated with FI.[43] However, in a recent cohort study (n = 39,181 residents) that analyzed development of double FI after admission, the authors found no statistically significant correlation between black race and double FI (HR = 1.05, 95% CI 0.97-1.13).[18] These results are inconsistent with a previous study that found FI was approximately twice as prevalent among white women (20%) as compared to black women (11%).[52]

Stroke

The effect of stroke was analyzed by 5 studies, of which 4 studies showed that stroke does not increase rate of FI.[10,37,40,43] Only 1 study found stroke to be significantly correlated with FI.[34]

Potentially modifiable correlates, in the context of this review, are those factors associated with FI that individual resident, nursing staff, or policy makers have the potential to improve. The most commonly reported potentially modifiable correlates of FI from the studies are ADL, diarrhea, urinary incontinence, constipation, reduced mobility, and the use of laxatives (Table 2).

Discussion

This is the first review that systematically investigates the prevalence, incidence, and correlates of FI specifically related to older people living in care homes. Although 4 systematic reviews have been published previously on prevalence of FI,[1,2,13,53] those reviews concentrated on the general population. The characteristics of the care home population, advanced age, frailty, and high comorbidities (i.e., dementia)[10] suggest that they require different care pathways from the general population. Younger populations have fewer cognitive impairments and fewer episodes of incontinence.[44] In one study, age <65 years was found to be a protective factor for not developing FI.[38]

This review showed that double FI is more prevalent among older people living in care homes compared to isolated FI. This raises awareness for appropriate assessment to unravel the underlying causes of double FI when an older person is admitted to a care home. The review did not find literature in this population in which staff considered soiling as FI or not. In the studies included, FI was usually reported by staff rather than residents, probably because most residents are likely to have some degree of cognitive impairment. The figures represented in this review reflect what staff considered as having FI. Hence, the issue of whether the residents considered themselves as having FI is unknown. Dementia or cognitive impairment is the most consistently reported correlate of FI. Previous studies have found dementia or cognitive impairment as an influencing factor for care home admission.[12,54] There are suggestions that care home residents with dementia experience increased FI, and that over time they experience the highest increase in care dependency compared with residents without dementia.[18] In this review, dementia was a documented risk factor for FI, but its effect on the uptake of different interventions and the dementia-specific continence and toileting skills that staff require remain unknown. A recent review argues that addressing the specific challenges (e.g., recognizing the urge to defecate, remembering where the toilet is) that arise when providing continence care to people with dementia is likely to be key to helping to reduce FI in this population.[55]

Many people with FI also experience urinary incontinence, hence the term double fecal incontinence. This review found high prevalence of double FI among older people living in care homes. There is evidence to suggest that double FI becomes worse over time following a care home admission among older people.[18] This could be explained by several factors, including deterioration in functional ability with advanced age, poor institutional practices such as poor bowel care, introduction of new types of food, inappropriate use of laxatives, side effects of polypharmacy, or perhaps fecal impaction due to a sedentary lifestyle. Some of these factors need consideration when developing interventions to prevent or reduce double FI among older people resident in care homes. Consistent with previous reports,[4,27,34,37,40] this review found that impairment in components of ADL is a major influence on FI. This is amplified for residents who also live with dementia.[12] These combined factors present an individual with significant difficulty in maintaining independent FI because socially acceptable defecation involves a sequence of events such as the ability to walk to the toilet, and the dexterity to undress and then dress, and the comprehension to evacuate the bowel appropriately.

The correlation between ethnicity and FI was surprising, as there seems no physiological reason that explains this. It is perhaps due to cultural influences. Conversely, this could also be the result of how health care staff relate to people of different race and ethnicity. The way researchers sometimes report their findings may also explain the correlation. A study conducted in the United States to assess black-white disparities in care homes [reported as nursing homes] reported that black people in care homes were treated far worse compared to whites: more physical restraints, more antipsychotic medication, and more frequent use of feeding tubes. However, on inspection of the data the authors used, 90.9% (n = 1,458,823) were whites and only 9.1% (n = 146,891) were black.[56] A further robust research study in different regions such as Europe or Australia, taking into consideration the representativeness of participants, is recommended.

The clinical implications of this review's findings are that, apart from aging process, there are several underlying factors associated with FI, such as loose stool and ADL that require further assessment when older people are admitted to a care home.

Limitations of the Evidence Base

All but 1 study was an observational study, so causality cannot be inferred from this review. Heterogeneity in study designs, characteristics of populations, FI diagnostic criteria, data collection methods, and outcome measurements precluded pooling of data for a meta-analysis. This means that the true prevalence rate remains unknown. Not all were high-quality studies. Two-thirds of the residents were female, and all the studies were conducted in middle- and high-income countries. The studies were carried out in predominantly white residents. Therefore, transferability of results from those studies to low-income countries, male gender, or nonwhite care home population requires further research.

Several studies had different study aims other than the outcomes of interest in this review. In some instances, care home data were extracted from studies that also included populations in other health care settings. Therefore, we acknowledge bias in assessing our outcome measures because compared with studies solely dedicated to investigating FI, those investigating FI as a secondary outcome or as part of a generalized bowel function or care home assessment might be less accurate.

The literature in frail older people in care homes has not, with rare exceptions, attempted to characterize FI according to possible physiological subtypes of the condition. No study in this review reported outcomes based on etiology or mechanism of FI. This is reflected in the FI typology reported in this review, which is how the authors of included studies reported their findings. This, arguably, provides only limited guidance for clinicians and therefore points out the need for further research.

Conclusions and Implications

FI is prevalent among older people living in care homes. Correlates of FI including limits to ADL, reduced mobility, UI, laxative use, and problems with stool consistency (constipation and diarrhea) are potentially amendable to intervention. Our findings suggest the need for interventions to account for the multifactorial underlying causes of FI to reduce the risk and impact of the condition. This is important for care home residents, their relatives, and staff in care homes. An intervention that recognizes and incorporates knowledge and staff training about what supports dementia-specific bowel care and how the care home culture and environment affects uptake and potentially modifiable correlates of FI require further research. The need for a consensus on how FI in care home residents is recognized, reported, and researched to ensure future work captures specific characteristics of the care home population is recommended.

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Chapter 3: Interventions for treating or managing faecal incontinence in older people living in care homes (Review)

This section presents the evidence-based, Cochrane Systematic Review led by the PhD candidate which synthesises the evidence for treating or managing faecal incontinence (FI) in older people living in care homes. The review (Musa et al. [submitted]; PhD Paper-2) answers the question raised by Chapter 1 on what evidence-base interventions exist to manage faecal incontinence among older people living in care homes.

The review contains a justification for the databases used and for the search terms and filters chosen for the systematic search. A statement of the contribution of the PhD candidate to this review appears at Pages 67, 77, and 96 of this thesis. All appendices in the review are relabeled as “PhD Paper 2” at the end of the thesis to enhance presentation.

One of the key aspects of evidence-based practice is the development of methods for the synthesis and integration of primary research, in the form of systematic reviews (Bunn et al., 2014). Systematic reviews have been regarded as particularly important tools for decision-makers as it inherently makes sense for decisions to be based on amalgamation of evidence rather than a single study (Salandra et al., 2021). The Cochrane Collaboration is an independent, international organisation (with over 130 countries) involved in preparing, maintaining, and disseminating systematic reviews evaluating the effectiveness of health-care interventions (Cochrane Database of Systematic Reviews (CDSR), 2022). The Cochrane systematic reviews are among the most reliable sources of evidence relating to the best available evidence generated through research to inform decisions about health (Bunn et al., 2014, Menon et al., 2021, Salandra et al., 2021). The Cochrane systematic reviews are prepared by health professionals with editorial teams overseeing the preparation and maintenance of the reviews, as well as the application of the rigorous quality standards. In the UK, for example, Cochrane systematic reviews are used to inform the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) guidelines, NICE Clinical Knowledge Summaries and NHS Shared Decision Making –

patient decision aids (CDSR, 2022). The UK National Institute for Health Research (NIHR) systematic review programme currently supports 20 Cochrane Review Groups (CRGs) that have their editorial bases in academic or health institutions (Bunn et al., 2014).

For the current review, the PhD candidate firstly developed a protocol and submitted this for peer review. This process resulted in some minor adjustments to the original protocol and addition of a plan to carry out health economics evaluation (hence the inclusion of a health economist co-author). The protocol was published by the Cochrane collaboration (Musa et al., 2018). No included study in the full review (Musa et al. [submitted]) included an economic evaluation; therefore, no economic analysis was carried out.

The current review included only randomised control trials (RCTs) because in the hierarchy of evidence, systematic reviews of RCTs offer the highest level of evidence (Menon et al., 2021, Salandra et al., 2021, Skivington et al., 2021). However, as with many Cochrane reviews, because only RCTs are included, a very limited evidence base is reported, highlighting the almost non-existence of high-quality evidence on managing FI in CHs. This limits the usefulness of the review in guiding clinical practice. Hence the need for further development and exploration of what is needed for FI in care homes.

Interventions for treating or managing faecal incontinence in older people living in care homes (Review)

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ABSTRACT

Background

Faecal incontinence is a debilitating health condition that affects people of all ages, but it is more prevalent among older people living in care homes. Faecal incontinence affects more than half of all older people living in care homes. It has significant emotional impact that affects not only the person that experiences the condition, but also his/her family members and care workers. In frail older people, faecal incontinence has multiple causes such as functional inability to reach a toilet facility in time, side effect of polypharmacy and comorbidity (e.g., dementia), as well as bowel problems such as diarrhoea or constipation. Inappropriate continence care can lead to reduced quality of life, and in some cases, it is associated with death. Therefore, continence care in frail older people living in care homes requires consideration of the potential role of carers and the care environment, comorbidity, current medication use, and functional as well as cognitive impairment among the older people living in care homes.

Objectives

To assess the effects of interventions for treating or managing faecal incontinence in older people living in care homes.

Search methods

We identified relevant trials from the Cochrane Incontinence Specialised Register. To summarise, the Register contains trials identified from the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, MEDLINE In-Process, MEDLINE Epub Ahead of Print, ClinicalTrials.gov, WHO ICTRP, UK Clinical Research Network Portfolio and hand-searching of journals and conference proceedings. Many of the trials in the Cochrane Incontinence Specialised Register are also contained in CENTRAL. The latest search for this review was conducted on 03.03.2022.

Selection criteria

Three review authors (MKM, AGV, and CN) independently examined the titles and abstracts of all potentially eligible studies obtained from the database search in accordance with the inclusion criteria. The same three review authors carried out full-text screen of potential papers to assess their eligibility for the review. Disagreements were resolved by consultation with a fourth review author (CG or RH). Three review authors (MKM, LB, and CN) independently assessed the risk of bias of included studies using Cochrane's Risk of Bias tool.

Data collection and analysis

Three review authors (MKM, AGV, and CN) independently extracted data from the included research studies. A modified version of the Cochrane-developed data collection form for intervention reviews was used, which was piloted on a sample of included studies to determine suitability. The following information was extracted from eligible studies: study design and setting, participant characteristics, details of the intervention(s) given, and the outcomes assessed. Where clarification was needed or the data were unclear from included studies, an attempt to contact the authors was made, particularly if it would be possible to provide separate data for older participants that resided in care homes. The three review authors then compared their extracted data to ensure accuracy. The final data was entered into the Review Manager software (RevMan 2020).

Main results

We included four studies. These studies included 471 participants and examined the effect of 4 interventions. However, the four studies were all low quality and none of them had data suitable for inclusion in a quantitative analysis. Therefore, we present only a narrative summary of the results and are unable to draw any meaningful conclusions, except that there is a complete lack of high-quality evidence on this topic. We had planned to develop a brief economic analysis to summarise the main findings of relevant economic evaluations, but we did not identify any such studies.

Authors' conclusions
We have very low-certainty evidence for all interventions considered in this review on whether any of them can reduce frequency or impact of faecal incontinence episodes among older people living in care homes. Given the high prevalence and burden of the condition in care homes, the complete absence of high-quality evidence on which to base care is a real gap in knowledge on how to care for older people in this setting. With an ageing population, there is an urgent need for research in this area.

3.1 Plain Language Summary

Interventions for treating or managing faecal incontinence in older people living in care homes

Review question: Which interventions work to reduce episodes of faecal incontinence among older people living in care homes?

Background
Faecal incontinence, which means defaecating involuntarily (or defaecating before reaching a toilet facility), is more common among older people living in care homes compared with the general adult population. Many older people living in care homes are frail and dependent on care staff for assistance with activities of daily living (e.g., going to the toilet, washing, dressing, etc.), have many underlying health problems (for which many are prescribed several medications), and/or dementia.
Faecal incontinence remains a taboo topic because many people are too embarrassed to talk about the condition with relatives, friends, or medical professionals. It can affect the quality of life of the person with the condition. For example, people that experience faecal incontinence may feel ashamed to attend public gatherings for fear of the embarrassment that the faecal leakage may cause them. This may cause them to isolate themselves, and eventually develop depression. When not appropriately managed, faecal incontinence may cause a moisture lesion or pressure ulcers to the skin of the older person, which can be a source of infection with the consequence of severe illness and pain. Faecal incontinence can also affect the turnover of care staff because many people do not like to deal with someone else's stool. It is costly to manage in terms of both incontinence products and staffing needed to manage it.
There is a lack of evidence of the most effective interventions to reduce frequency of faecal incontinence episodes in older people living in care homes.

How up to date is this review?
The evidence in this review is current up to 03rd March 2022.
Study characteristics
Our search identified four studies for this review, which included twenty-three care homes, including 471 residents with a mean age between 84 and 88. Of these residents, the majority (77% to 81%) were females. None of the studies reported on the severity of faecal incontinence at the start of the study, or racial/ethnic differences. The four included studies tried four different bowel care interventions, namely: (1) the effect of endurance and strength (or functional incidental training), (2) the effect of a multi-component intervention that included physical activity and mobility endurance, and food and

fluid intake, (3) the effect of a twelve 30-minute sessions of transcutaneous posterior tibial nerve stimulation, and (4) the effect of staff educational training.

Funding sources of included studies

The four studies that met inclusion criteria were funded as follows: Glasgow Caledonian University Institute for Applied Health Research Pump Priming Award funded Booth 2013; Sør-Trøndelag University College, allocation of PhD scholarship from Norwegian Ministry of education and Research, and the Norwegian Nurses Organization funded Blekken 2015; the National Institutes of Health: Mobility and Incontinence Management Effects on Sickness and Grant and the National Institute on Aging funded Schnelle 2002; and Grants AG2355501A1 and AGO28748 provided by the National Institute of Aging and the Veterans Affairs Medical Research funded Schnelle 2010.

Key results

It was not possible to use information from the studies to judge the overall effectiveness of interventions. Therefore, we provide a simple description of the results of the four studies, none of which were high quality in this review. Only one of the four studies had a primary focus on faecal incontinence (Blekken 2015). The other studies mostly concentrated on urinary incontinence. No study provided sufficient data to enable analysis or pooling of the results.

Certainty of the evidence

We did not find any evidence to answer our review question.

SUMMARY OF FINDINGS

Summary of findings 1. Conservative management versus no intervention/placebo/sham/care as usual

Conservative management compared with no intervention, placebo, sham or care as usual for faecal incontinence in older adults living in care homes

Patient or population: older people living in care homes with faecal incontinence

Settings: care homes

Intervention: conservative management

Comparison: no intervention, placebo, sham, care as usual

Outcomes	Illustrative comparative risks* (95% CI)		Relative effect (95% CI)	No of Participants (studies)	Certainty of the evidence (GRADE)	Comments
	Assumed risk	Corresponding risk				
	No intervention, placebo, sham, care as usual	Conservative management				
Cure and improvement of FI: latest time-point	**[value] per 1000**	**[value] per 1000** ([value] to [value])	**RR [value]** ([value] to [value])	[value] ([value])		Reported but not in the format suitable for this table. Narrative of findings is given in the summary of results section.
Reports of behaviours related to FI and dementia: latest time-point	-	-	-	-	-	Not reported
Adverse effects relating to interventions: latest time-point	-	-	-	-	-	Not reported
Measures of psychological well-being: latest time-point	-	-	-	-	-	Not reported
Health economic measures: latest time point	-	-	-	-	-	Not reported

*The basis for the **assumed risk** (e.g. the median control group risk across studies) is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).

CI: Confidence interval; **RR:** Risk Ratio;

GRADE Working Group grades of evidence
High certainty: Further research is very unlikely to change our confidence in the estimate of effect.
Moderate certainty: Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
Low certainty: Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.
Very low certainty: We are very uncertain about the estimate.

Note from editorial base: please use the footnotes to explain your GRADE downgrading decisions using the following format:
“We downgraded (X) levels for (serious/very serious) (GRADE consideration) due to (brief description of support for judgement)” e.g. "We downgraded (1) level for serious limitations in study design due to most of the studies being at high risk for selection bias."

3.2 Background

Description of the condition

Faecal incontinence (FI) is the involuntary expulsion of faecal material, which can be either liquid or solid consistency, through the anus, or inability to defer defaecation to reach the toilet in time due to functional or cognitive limitations (International Continence Society (ICS) 2021; Musa 2019; NICE 2007). It is a socially debilitating and embarrassing condition that has a huge impact on the quality of life and activities of daily living (ADL). Many people with the condition, including older people in care homes, are embarrassed or ashamed to discuss their problem with healthcare professionals or even with friends and family; in addition, healthcare practitioners do not routinely broach the topic during consultations (Godfrey 2007; Johanson 1996; NICE 2007; Norton 2012). FI affects people of all ages, but it is more prevalent among older people in care homes, particularly those living with dementia (Musa 2019).

Care homes include facilities that provide accommodation and 24-hour on-site nursing care for persons who need support with ADLs (e.g., nursing homes), and those that provide domestic-style residency where nursing needs are met by visiting nurses (e.g. residential care homes) (Musa 2019; Sandford 2015; Underwood 2013). Internationally, the model of care is broadly similar, but titles of care facilities vary. For example, care homes may be called assisted living facilities, aged-care facilities, skilled nursing facilities, long-term care setting, long-term care services, long-term geriatric care, or veteran homes. This review includes care homes with and without on-site nursing care provision, where personal care is provided, and the older persons need help with their ADL. Many people in this setting will be dependent on staff because of physical or cognitive limitations, or both and may only be continent if assistance is available when such need arises (often termed as 'dependent continence') (Jerez-Roig 2015; Stokes 1987).

Most older people living in care homes are frail, in their last year(s) of life, living with multiple health problems, and often take many drugs (known as polypharmacy) (Age UK 2017; Alzheimer's Society 2017; British Geriatrics Society 2016). Approximately 60% to 80% of care home residents have dementia (Alzheimer's Society 2017; OECD 2011; Sampson 2018). The most frequently reported correlates of faecal incontinence in this population are cognitive impairment, limited functional capacity, urinary incontinence, reduced mobility, advanced age, and diarrhoea (Musa 2019). It is, therefore, important to distinguish interventions that are applicable to this subgroup of the population and care setting from the general population or younger people living in care homes who have different characteristics and underlying causes of FI. Continence care in frail older people living in care homes needs to consider the care home environment and care staff and the potential role of comorbidity, current medications use (prescribed, over the counter and/or naturopathic), and functional and cognitive impairment of a care home resident (Goodman 2017).

The prevalence of FI, as reported in research studies, ranges from 6% to 10% in the general population (Landefeld 2008), and up to 57% in older people living in care homes (Ihnát 2016). Evidence suggests that most people in care homes with FI also have urinary incontinence, a situation commonly described as 'double incontinence' (Saga 2013). The rate of isolated FI (without urinary incontinence) among care home residents is higher than in the community-dwelling population of the same age (Ditah 2014; Halland 2013). A recent systematic review reported the medians of reported isolated faecal incontinence, double incontinence, and all faecal incontinence (that is whether isolated or double incontinence) as 3.5% [interquartile range (IQR) = 2.8%], 47.1% (IQR = 32.1%), and 42.8% (IQR = 21.1%), respectively (Musa 2019). FI affects both men and women equally in the care home setting (Saga 2013; Whitehead 2009).

Faecal incontinence can have multiple causes and can arise from a complex interplay of physiological, environmental and psychosocial factors (Madoff 2004; NICE 2007). A complex sequence of activities (for example, the need to walk to the toilet facility, or undressing) is required to accomplish bladder and bowel continence (Stokes 1987). In frail older people, this sequence may be compromised at any point, resulting in FI. Maintaining continence requires the interaction of an intact and functional anal sphincter complex, anorectal sensation and rectal capacity, the consistency of the faeces (ideally formed but not hard), adequate cognitive ability and physical mobility, and bowel motility (Ijaola 2010; Stokes 1987). Any impairment of these elements can result in incontinence and for many individuals more than one factor applies. These symptoms are stigmatising and are often a burden to families and care providers. In some cases, incontinence may contribute to institutionalisation of older people because they feel embarrassed to socialise or participate in activities (Madoff 2004). Once a person is resident in a care home, the condition is so widespread that FI can become normalised (Stokes 1987). Continence care breaches social norms about privacy and bodily functions (Butcher 2020). It is costly to manage FI in the community setting (Xu 2012) but to date, there is no information on the specific costs of FI in care homes. It is predicted to be costly in terms of staff time and products used to manage it. Disruption of normal anatomy and function of the anal sphincter complex caused by obstetric or iatrogenic injury is the most common cause of FI in the general adult population (Madoff 2004; Rao 2004). However, in older people such injuries are not often the direct trigger for symptom onset. Reduced mobility, which results in an inability to reach the toilet in time, lack of cognitive capacity to recognise the need to go to the toilet, and uncontrollable faecal overflow due to rectal loading or faecal impaction play a bigger part in the pathophysiology of FI (Blekken 2016; Goodman 2017; Flanagan 2014). These may be complicated by dehydration and use of medications that influence bowel function or stool consistency and may also be precipitated by external prolapse of the rectum. Faecal incontinence may be a symptom of underlying bowel pathology, such as bowel cancer, and some people also experience FI as a consequence of pelvic cancer surgery or adjunctive radiotherapy or chemotherapy (Andreyev 2005).

Description of the intervention

Various interventions are available to treat and prevent FI. Below is a non-exhaustive list of possible interventions. Some of these interventions (e.g., surgery or biofeedback), may be less appropriate in older people living in care homes.

Conservative management

- Toileting and bowel management programmes: establishing access to a toilet and a routine of regular and complete rectal evacuation at predictable times is a common intervention, particularly in frail older people (NICE 2007). This may include individual programmes or care home personal care routines and policies.
- Education for care staff about the causes of FI and how to assess and provide care for residents with FI (Goodman 2017).
- Dietary advice or changes: this normally entails adjusting fluid and fibre intake, while avoiding foods that trigger symptoms (NICE 2007).
- Transanal irrigation: for underlying constipation and evacuation difficulties, transanal irrigation with water or saline can be used. With a specially designed device consisting of a water reservoir and catheter, fluid is instilled via the anal canal to empty the rectum (Christensen 2006).
- Pelvic floor muscle training with or without biofeedback: this option offers individualised training of the pelvic floor muscles, sphincter muscles and co-ordination using visual or auditory feedback (Norton 2012). This intervention requires that the person can comply with advice to conduct voluntary exercises.
- Non-implantable electrical stimulation: electrical stimulation, using a percutaneous or transcutaneous device, has been used to treat FI (Hosker 2007). This stimulation may be administered via the anal canal, vagina, perianal skin or remotely percutaneously or transcutaneously to the tibial nerve at the ankle (Booth 2013).
- Other conservative, alternative or complementary therapy: acupuncture, acupressure and herbal medicine have been used to alleviate symptoms (Sipaviciute 2021).
- Interventions for people living with dementia aiming to improve orientation and recognition related to bowel management and continence.
- Interventions such as exercise to improve mobility or functional ability to use the toilet (Schnelle 2010).
-

Drugs

- Drugs: for those with loose stools, medications such as a stool bulk forming agent or anti-diarrhoea medication can be used to firm up the consistency. Conversely, those with faecal impaction may be advised to use laxatives, suppositories or enemas to ensure evacuation of stool from the rectum (Omar 2013; Tobin 1986). It might also include a review and modification of medications for other conditions which have bowel side-effects, such as loose stool or constipation.

Containment

- Pads and anal plugs: pads are used for practical management and will minimise staining of underwear. Anal plugs offer temporary sealing of the anus (Deutekom 2015).

Surgery

- Sacral nerve stimulation (SNS): this uses an implantable electrical stimulation device (consisting of a 'pacemaker' and implanted lead, normally implanted in the buttock), which gives constant stimulation around the region of third sacral nerve root (Thaha 2015).
- Surgery: surgical interventions aim to restore the structural integrity of the sphincter complex (sphincter repair); supplement the existing sphincter complex (artificial sphincters, injectable bulking agent) (Maeda 2013); achieve faecal diversion (colostomy/ileostomy); or mechanically repair prolapse, potentially with functional restoration of normal anatomy (rectal prolapse repair) (Brown 2013; Fernando 2013; Tou 2015).

Why it is important to do this review

The world's population is aging. Increasing particularly rapidly is the number of people aged 65 years and above (OECD 2011; Office for National Statistics 2019). In 2019, for example, there were 703 million persons aged 65 years or over around the world. It is projected that by 2050 this will double to 1.5 billion (United Nations 2019). This trend of aging among older people is also noticeable in the United Kingdom (UK), where there are about 12 million people aged 65 years and older. Among this number, there are almost 1.6 million people aged 85 years and above, and more than 500,000 people are aged 90 years or older (Office for National Statistics 2019).

Meanwhile, there is a growing number of older people moving into care homes to receive help in fulfilling their ADLs (OECD 2011; ONS 2014). While some people living in care homes are healthy and independent, a significant number of them live with multiple health conditions and problems requiring nursing care. Faecal incontinence is one of the major health conditions that affects older people, but it is infrequently addressed (Madoff 2004), presumably because staff accept it as inevitable (Saga 2014). Faecal incontinence is a risk factor for elderly people to be placed in the care home, and the care home environment itself is a risk factor for developing incontinence (Leung 2008). Faecal incontinence has a major impact on the quality of life and dignity of those affected and their family, and it probably contributes to staff turnover due to the workload it creates in care homes (AlAmeel 2010; Damon 2006; Whitehead 2009).

Several Cochrane reviews have examined the efficacy of interventions for FI (Brown 2013; Deutekom 2015; Hosker 2007; Norton 2012; Omar 2013; Thaha 2015). However, older people living with complex needs, including those living with dementia in care homes, may respond differently to an intervention. It is the assumption of this review that care home residents are likely to have different characteristics and may benefit from different interventions compared to adults living at home or in other healthcare settings (Blekken 2016; Spilsbury 2015).

3.3 Objectives

To assess the effects of interventions for treating or managing faecal incontinence (FI) in older people living in care homes.

3.4 Methods

3.4.1 Criteria for considering studies for this review

Types of studies

We included individually randomised controlled trials (iRCTs), cluster-randomised controlled trials (cRCTs) and cross-over trials to assess interventions for treating or managing faecal incontinence (FI) in older people living in care homes. We also included quasi-randomised studies (where methods of allocation are deemed not to be strictly random such as alternation, date of birth, or case record number). We did not pre-specify a minimum length of follow-up for a trial to be eligible as life expectancy in the care-home setting is limited.

We included full economic evaluations (cost-effectiveness analyses, cost-utility analyses and cost-benefit analyses), cost analyses and comparative resource utilisation studies of any study design.

Types of participants

We included older people with FI who live in care homes, aged 65 years and above, or studies of people of mixed ages where the mean age of participants was 65 or above. Where a study contained a mixed participant sample (i.e., some lower than 65 years old but also contains data on participants over 65 years), we attempted to extract only the data that related to people aged 65 years and above.

We excluded reports where the mean age was below 65 years and where we could not obtain data on the outcomes of interest. We did not include trials in other care settings such as home care or hospitals.

We included long-term care-home residents, excluding short-term respite care (less than 30 days). However, we are aware some trials do not report these data. In this instance, we assumed that participants were long-term residents.

Types of interventions

We included the following interventions, either as single interventions or where these interventions were included as an element of a multi-component intervention, where FI was reported as an outcome.

- Conservative management: toilet regimens; staff training interventions; dietary changes; interventions to improve function, activities of daily living (ADL) or mobility (e.g. exercise programmes); transanal irrigation; pelvic floor exercises; biofeedback; anal stimulation, other forms of peripheral nerve stimulation; acupuncture, acupressure; continence advice, education, lifestyle advice, leaflets/brochures (aimed at residents or staff); interventions addressing orientation and recognition for people living with dementia.
- Drugs: anti-diarrhoea agents, stool-forming agents, suppositories and enemas, herbal medicine.
- Containment strategies: anal plugs, incontinence pads.
- Surgery: sphincter repair, sacral nerve stimulation, dynamic graciloplasty, artificial bowel sphincter, stoma formation.

We ordered the comparators by their importance to decisionmakers, clinicians and patients, with the first three of particular interest.

- Conservative management versus no intervention/placebo/ sham/care as usual.
- Drug management versus no intervention/placebo/sham/care as usual.
- One conservative management versus another conservative management.

- One conservative management versus drugs.
- Surgical management versus no intervention/placebo/sham/ care as usual.
- One surgical management versus another surgical management.
- One conservative management versus surgical management.
- Any containment strategy compared with any other intervention.

3.4.2 Types of outcome measures

Primary outcomes

- Cure and improvement of FI (measured by scores (e.g., Cleveland Clinic Fecal Incontinence Score (CCFIS) or St Mark's Incontinence Score), by a bowel diary, reported by patients or staff, or reported in a composite data set for care homes (such as the Minimum Data Set or interRAI) where the incontinence element of the score is reported separately).

Secondary outcomes

- Reports of behaviours related to FI and dementia (e.g., refusal to use a toilet, agitation, or smearing)

- Adverse effects relating to interventions (e.g., compromised skin integrity)
- Condition-specific quality of life scores (e.g., the Faecal Incontinence Quality of Life Scale (FIQL))
- Measures of psychological well-being, measured by validated tools such as the Hospital Anxiety and Depression Scale (HADS)
- Health economic outcomes e.g., cost of incontinence products, healthcare utilisation and skin care; and other health economic outcomes such as incremental cost-effectiveness ratios and incremental cost per quality adjusted life year (QALY)

Timing of outcome assessments

We included outcomes reported at any time point as life expectancy in the care home setting is often limited and long-term follow-up is often not possible.

Main outcomes for 'Summary of findings' tables

In accordance with guidance in the *Cochrane Handbook for Systematic Reviews of Interventions* (Deeks 2022), we included the above primary and secondary outcomes in the 'Summary of findings' tables.

3.4.3 Search methods for identification of studies

This review drew on the search strategy developed for Cochrane Incontinence. We did not impose any language or other limits on the searches described below.

3.4.4 Electronic searches

Review of effectiveness

We identified relevant trials from the Cochrane Incontinence Specialised Register. For more details of the search methods used to build the Specialised Register, please see the Group's webpages where details of the Register's development (from inception) and the most recent searches performed to populate the Register can be found. To summarise, the Register contains trials identified from the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, MEDLINE In-Process, MEDLINE Epub Ahead of Print, ClinicalTrials.gov, WHO ICTRP, UK Clinical Research Network Portfolio and handsearching of journals and conference proceedings. Many of the trials in the Cochrane Incontinence Specialised Register are also contained in CENTRAL.

The terms used to search the Cochrane Incontinence Specialised Register are given in Appendix 1 (See Appendix 7 at the end of the thesis).

We liaised with Cochrane Dementia and Cognitive Improvement's Information Specialist regarding a search of their Specialised Register (known as ALOIS) for reports of trials related to one of our interventions of interest: 'Interventions addressing orientation and recognition for people living with dementia where continence is reported as an outcome'. Details of ALOIS - including how it has been developed as well as the search terms used can also be found in Appendix 1 (See Appendix 7 at the end of the thesis). The search was last updated on 03rd March 2022.

Integrated full systematic review of economic evidence

We performed additional searches for the integrated full systematic review of economic evidence. A brief summary is given below with further details given in Appendix 2 (See Appendix 8 at the end of the thesis).

3.4.5 Economic evaluations

We searched:

- NHS Economic Evaluation Database (NHS EED) on the Centre for Reviews and Dissemination (CRD) website (covering to
- MEDLINE on OvidSP (covering 1 January 1946 to the most recent available version); and
- Embase on OvidSP (covering 1 January 1974 to the most recent available version).

We explored the usefulness of an additional search of the Health Technology Assessment (HTA) database, also on the CRD website, depending on a fuller report of the work of Arber 2017.

Cost-analyses and comparative resource utilisation studies

Search strategies were developed to locate cost analyses and comparative resource utilisation studies.

Searching other resources

We hand searched the reference lists of relevant articles.

3.5 Data collection and analysis

Selection of studies

Three review authors (MKM, AGV, and CN) independently examined the titles and, if available, abstracts of all possible eligible studies derived from the above search strategy in accordance with the inclusion criteria. We obtained the full paper for all studies considered potentially eligible. The same review authors then assessed eligibility of the full papers. We resolved any disagreements by consultation with a fourth review author (CG or RH). We made attempts to contact authors, particularly where papers were written in languages other than English to obtain an English version, or to obtain data used by the authors. If a study appeared eligible but authors had no available translation in English, we attempted to obtain a translation from within our teams. Where there were missing or unclear data, we contacted authors of identified articles in order to inform our study selection decision. Blinding to authorship of articles was not possible because review authors are knowledgeable in the topic area and likely to be familiar with articles.

3.6 Data extraction and management

Three review authors (MKM, AGV, and CN) independently extracted data from the included trials. We used a modified version of the Cochrane-developed data collection form for intervention reviews, which was piloted on a sample of included studies to determine suitability. During data extraction, we extracted the following information from eligible studies: study design and setting, participant characteristics (including age, adverse events and complications), details of the intervention(s) given, the outcomes assessed, the source of study funding and any conflicts of interest stated by the investigators. We also looked at quality criteria (i.e., randomisation and blinding) of all included studies. If clarification was needed or the data were unclear from included studies, we made attempts to contact the authors, particularly if it might be possible to provide separate data for older participants that reside in care homes. The review authors then compared their extracted data to ensure accuracy. The final data was entered into the Review Manager 5.4 software (RevMan 2020).

We developed a data extraction form for economic evaluations based on the format and guidelines used to produce structured abstracts of economic evaluations for inclusion in the NHS Economic Evaluation Database (NHS EED), adapted to the specific requirements of this review.

3.6.1 Assessment of risk of bias in included studies

Three review authors (MKM, LB and CN) independently assessed the risk of bias of included trials using Cochrane's 'Risk of bias' tool (Higgins 2011). We assessed the following domains: selection (random sequence generation; allocation concealment); performance (blinding of participants and personnel); detection (blinding of outcome assessors); attrition (completeness of outcome data); selective reporting (reporting bias); and other sources of bias. Any disagreements were resolved by discussion with a fourth review author (CG or RH). We describe all judgements fully and present our conclusions in the 'Risk of bias' table (please see Characteristics of included studies in appendix).

We rated studies with over 20% loss to follow-up as having a high risk of attrition bias. We rated studies that reported outcomes according to a published protocol as having a low risk of reporting bias. Where a published protocol was not available, we assessed trials that reported at least one of our outcomes as having an unclear risk of bias.

Assessment of the overall methodological quality of included economic evaluations based on single empirical studies was informed by the application of a combination of Consolidated Health Economics Evaluation Reporting Standards (CHEERS) statement (Husereau

2013), and the CHEC Criteria list for the assessment of methodological quality of economic evaluations (Evers 2005). Assessment of the overall methodological quality of model-based economic evaluations was informed by the application of the CHEERS statement (Husereau 2013) and the NICE 'study limitations' checklist (NICE 2015).

We used the Cochrane 'Risk of bias' tool to assess economic evaluations based on single RCTs, including model-based evaluations. We used the Risk Of Bias In Non-randomized Studies of Interventions (ROBINS-I) tool to assess economic evaluations based on non-randomised studies, including model based evaluations based on a single study (Sterne 2016). For model based economic evaluations based on reviews of the results of two or more studies, we used the ROBIS tool (Whiting 2016).

3.6.2 Measures of treatment effect

Where dichotomous data were pooled, we used the number of events in intervention and comparison groups of each study to calculate Mantel-Haenszel risk ratios (RRs). Where continuous data were pooled, we calculated mean differences (MDs) between groups if studies reported exactly the same outcomes. If investigators reported similar outcomes on different scales, we calculated standardised mean differences (SMDs). We present 95% confidence intervals (CIs) for all outcomes.

3.6.3 Unit of analysis issues

We assessed trials for non-standard designs (e.g. cross-over trials and cluster-randomised trials (cRCTs)). We present results as reported by authors: per individual resident, or by care home randomised. For cRCTs, we were particularly aware of biases such as recruitment bias, baseline bias, loss of cluster, incorrect analysis, and comparability with RCTs.

We considered using the intra-cluster correlation coefficient (ICC) where there are both cRCTs and iRCTs because we were aware that, in the former, outcomes may depend on the enthusiasm, skill or training of the health professional delivering the intervention whereas, in the latter, outcomes may be purely based on group allocation (Flight 2016).

3.6.4 Dealing with missing data

We assessed trials on an intention-to-treat (ITT) basis as far as possible and attempted to obtain missing data on the number and reasons for withdrawals and dropouts from the authors. We reported levels of missing data as reported by authors.

3.6.5 Assessment of heterogeneity

We planned to scrutinise studies to ensure that they were clinically homogeneous in terms of participants, intervention, comparator, and outcome. We planned to use the Chi^2 test for heterogeneity (at 10%) or the I2 statistic to look for further differences between trials. If there were concerns about heterogeneity, we planned to use a random-effects model. We planned to assess statistical heterogeneity between trials using the I^2 statistic, taking an I^2 greater than 50% as indicating substantial heterogeneity using the rough guide provided in the Cochrane Handbook for Systematic Reviews of Interventions (Deeks 2022):

- 0% to 40%: might not be important.
- 30% to 60%: may represent moderate heterogeneity.
- 50 to 90%: may represent substantial heterogeneity.
- 75% to 100%: considerable heterogeneity.

3.6.6 Assessment of reporting biases

A comprehensive search and alertness to duplication of data attempted to detect publication and other reporting bias. We would have assessed the potential for reporting bias by funnel plot if 10 or more studies were included in an analysis (Higgins 2011), but this was not the case.

3.7 Data synthesis

To summarise the study characteristics, we conducted a narrative synthesis of all the included studies using Review Manager 5.4 (RevMan 2020).

We had planned to summarise economic evaluations using additional tables and to tabulate unit cost data, when available. We also planned to report the currency and price year applicable to measures of costs in each original study alongside measures of costs, incremental costs and incremental cost-effectiveness. Where details of currency and price year were available in original studies, measures of costs, incremental costs and cost-effectiveness would have been converted to 2018 International Dollars value using implicit price deflators for GDP (Gross Domestic Product) and GDP Purchasing Power Parities; Shemilt 2010). However, all our included studies did not provide data to do these.

3.7.1 Subgroup analysis and investigation of heterogeneity

We planned to combine trials only if the interventions were clinically similar enough. Had data allowed, we would have carried out the following subgroup analyses:

- participants with and without co-morbidities.
- participants with and without cognitive impairment (e.g., dementia).
- ambulatory versus immobile people.
- residential care homes (i.e., assisted living facilities) versus nursing homes (i.e., skilled nursing facilities or rest homes).

3.7.2 Sensitivity analysis

Had the data not suggested substantial heterogeneity, we planned to explore possible explanations by undertaking sensitivity analyses. In particular, we planned to carry out sensitivity analyses for the following.

- The risk of bias of trials.
- Cluster-randomised trials (cRCTs): what values of the intra-class correlation coefficient (ICC) should be used when trial analyses have not been adjusted for clustering?
- Cross-over trials: what values of the within-subject correlation coefficient should be used when this is not available in primary reports?
- Quasi-randomised controlled trials: what effect would blind or unblind outcome assessment have on overall results?

3.7.3 Summary of findings and assessment of the certainty of the evidence

We planned to prepare 'Summary of findings' tables for the main comparisons if there was sufficient evidence using the GRADEpro software (GRADEpro GDT 2015). The aim was to evaluate the overall quality of the evidence for the primary and secondary outcomes listed in the Types of outcome measures. We planned to use the GRADE criteria (risk of bias, consistency of effect, imprecision, indirectness and publication bias) to assess the quality of the body of evidence as it relates to the studies which contributed data to the conclusions of the review for the pre-specified outcomes (Atkins 2004; Schünemann 2011).

However, the studies we identified did not allow 'Summary of findings' tables to be presented for comparisons (see Summary of findings table above). For the same reason, we did not use the GRADE criteria. This will be reconsidered in future updates of the review if more data become available.

3.8 Results

Description of studies

Results of the search

A total of 1709 records were identified by a search of the Cochrane Incontinence Specialised Register. Seven reports of 6 studies were identified by a search of the Cochrane Dementia and Cognitive Improvement's Specialised Register (known as ALOIS) - after removal of duplicates. No additional records were identified from searching reference lists of included studies.

Of the 1709 records identified, 1662 were not relevant to the review topic; 42 studies were excluded for not meeting eligibility criteria. We could not get additional information from the main author of one of the articles (Chassagne 2000); therefore, we classified it as 'study awaiting classification' in accordance with guidance in section 4.6.3 of the Cochrane Handbook (Deeks 2022) (Appendix 10).

Included studies

We included four studies in this review. Two of the studies were conducted by the same lead researcher in the USA (Schnelle 2002 and Schnelle 2010), one study was carried out in Norway (Blekken 2015), and another study was carried out in the UK (Booth 2013).
Further details on individual included studies can be found in the Characteristics of included studies (Appendix 10).

Designs
The four studies that met eligibility criteria for this review included two randomised controlled trials (RCTs)(Schnelle 2002 and Schnelle 2010), a pilot study of clustered randomised controlled study (Blekken 2015), and a pilot randomised single blind, placebo-controlled trial (Booth 2013).

Sample sizes
The sample sizes for the included studies are as follow: Schnelle 2002 (n=256), Schnelle 2010 (n=112), Booth 2013 (n-30), and Blekken 2015 (n=73) respectively.

Setting
The studies were carried out in 13 nursing homes, 7 residential homes and 3 sheltered accommodation complexes. This review classified all those different care settings as 'care homes'.

Participants
All four studies included care home residents as participants, and one of the studies (Blekken 2015) also recruited nursing staff as participants.

Interventions
The four included studies investigated diverse interventions. One study provided educational interventions to staff in the form of one educational meeting that lasted for 7 hours (Single Intervention (SI) Group), SI + opinion leader + educational outreach (Multiple Interventions (MI) group), and a Control group which received no educational support from the researchers (Blekken 2015). Another study compared a 12-session programme of transcutaneous posterior tibial nerve stimulation (TPTNS) with a sham (placebo) stimulation (Booth 2013). Two studies provided a similar functional improvement intervention, with one of the studies referring to such intervention as endurance (standing, walking, and ambulating wheelchair) (Schnelle 2002), and another study referring to it as physical activity and mobility endurance (Schnelle 2010). As well as the physical activity and mobility endurance interventions, Schnelle and colleagues also provided two additional interventions: modified food and fluid intake, and incontinence care and prompted voiding (Schnelle 2010). Further details of each intervention are given in the (Appendix 10: Characteristics of included studies).

Outcomes
Only one study had FI as the primary focus (Blekken 2015) and that study was primarily a feasibility study which focused on feasibility outcomes, rather than FI outcomes, as a prelude to a larger planned subsequent study (the latter has not been published). The other three studies focused on urinary and faecal incontinence outcomes together, with an emphasis on the former. This review focused only on the FI outcomes pre-specified above. As the main focus of three of the studies was urinary incontinence, these studies had only very minimal outcomes reported for FI. All the four studies used different FI measures (See Appendix 10: Characteristics of included studies) for details of the outcome measures used).

Excluded studies
Most studies were excluded because either they were interventions not relevant to this review; were not a randomised controlled trial; were conducted in geriatric psychiatry in hospital or acute hospital settings (hence, not a care home population); on participants without FI, or the study did not measure FI as an outcome (Cochrane Handbook, Section 4.6.3; Version 6); the study compared two forms of laxatives without FI measures (Cochrane Handbook, Section 4.6.3; Version 6); or the study focused on cost of assessing and treating acute conditions other than FI.
Further details can be found in Characteristics of excluded studies (Appendix 11).

Risk of bias in included studies

Below we present the results of our 'Risk of bias' assessment (see Figure 1 and Figure 2). Further details can be found in the 'Risk of bias' tables.

Figure 1. Risk of bias graph: review authors' judgements about each risk of bias item presented as percentages across all included studies.

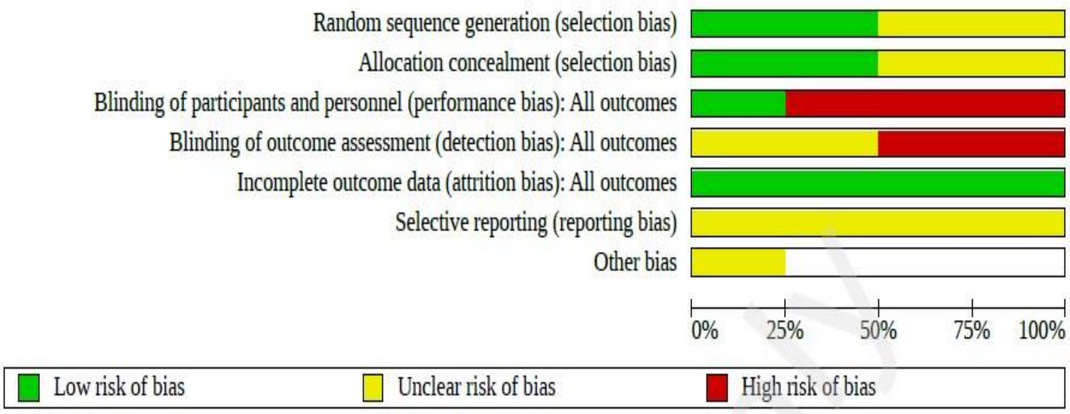
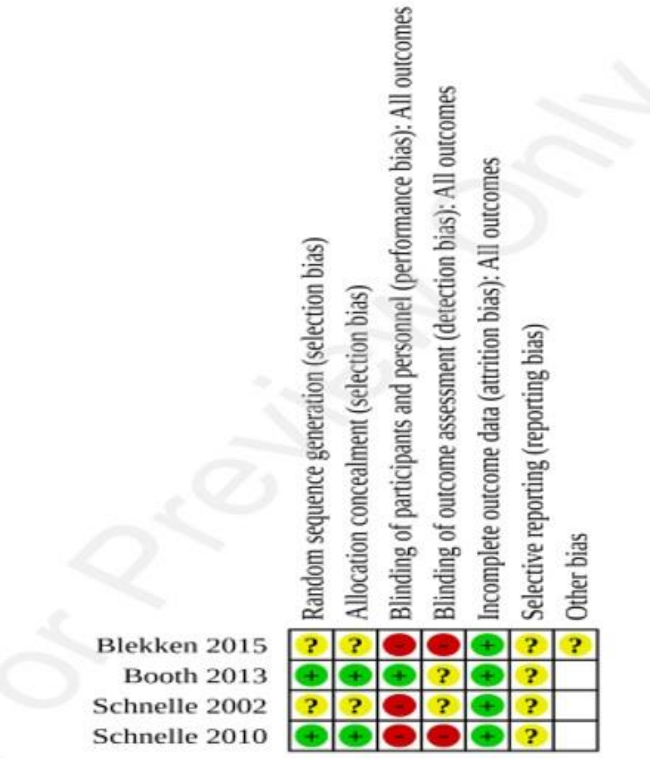


Figure 2: Risk of bias summary: review authors' judgements about each risk of bias item for each included study.



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias): All outcomes	Blinding of outcome assessment (detection bias): All outcomes	Incomplete outcome data (attrition bias): All outcomes	Selective reporting (reporting bias)	Other bias
Blekken 2015	?	?	-	-	+	?	?
Booth 2013	+	+	+	?	+	?	
Schnelle 2002	?	?	-	?	+	?	
Schnelle 2010	+	+	-	-	+	?	

Allocation

Random sequence generation

Randomisation was described clearly in two of the four studies (Schnelle 2010; Booth 2013), which we rated low for risk of bias, and was not sufficiently described in two studies (Blekken 2015; Schnelle 2002) which we rated unclear for risk of bias.

Allocation concealment

We rated two studies at low risk of selection bias (Schnelle 2010; Booth 2013), as the method of random allocation of participants to intervention and control groups and allocation concealment was described. We rated the other two studies as unclear risk of selection bias and allocation concealment (Blekken 2015; Schnelle 2002), because they did not provide enough information (or none at all) about their selection and allocation concealment process.

Blinding

Binding of participants and personnel

We rated one study at low risk of performance bias as all staff and participants were blinded (Booth 2013), one study was rated at unclear risk because blinding is not typical in clustered randomised control trials (Blekken 2015), and two studies at high risk because either independent outcome assessors could not blind researchers implementing the intervention (Schnelle 2002), or blinding of residents and research staff doing the intervention was not possible (Blekken 2015; Schnelle 2010).

Blinding of outcome assessment

We rated two studies at high risk of detection bias (Blekken 2015; Schnelle 2010), and the other two studies were rated at unclear detection bias because they did not provide information for a judgement (Booth 2013; Schnelle 2002).

Incomplete outcome data

Attrition bias was judged as low in all included studies because they provided enough information for judgement.

Selective reporting

All four studies included in this review lacked enough information in their report to judge whether they had reported all outcomes, and so were rated as unclear.

Effects of interventions

See: **Summary of findings 1** (Table 1 above): Conservative management versus no intervention/placebo/sham/care as usual

Please see summary of main results below.

Conservative management versus no intervention/placebo/ sham/care as usual

All four included studies used a type of conservative intervention and compared it to a sham intervention or care as usual.

Primary outcomes

Cure and improvement of FI

We did not find study which measured cure of FI. However, all four included studies in this review provided information (either narratively, or through numerical data contained in tables and/or graphs) on improvement of FI episodes. Summary of the outcomes are provided below (Table 2).

Table 2: Summary of the main result

Study	Intervention	Faecal Incontinence Outcome
Schnelle 2002	Functional incidental training (endurance and strength) vs Care as usual	The authors reported that the endurance and strength training intervention reduced frequency of FI from 7% of pad checks at baseline to 3% after 32 weeks of intervention, as compared with 6% at baseline to 7% after 32 weeks in the care as usual group; however, these differences were not statistically significant.
Schnelle 2010	Multicomponent (Physical activity and mobility endurance, and food and fluid intake) vs Care as usual	The authors reported that the interventions did not change the frequency of FI episodes.
Booth 2013	Twelve 30 minutes sessions of TPTNS vs Sham/placebo	The authors reported that faecal leakage improved in 47% of the TPTNS group compared with 23% of the sham group (P>0.106); however, these differences were not statistically significant.
Blekken 2015	Staff educational training (single educational training and multiple educational training vs Care as usual	The authors reported that FI was: 12% at baseline compared with 10% at follow-up, with a mean difference -0.03 (SD=1.32) in the SI group; 9% at baseline compared with 8% at follow-up, with a mean difference -0.37 (SD=0.92) in the MI group; and 14% at baseline compared with 16% at follow-up, with mean difference 0.57 (SD=1.15) in the control group, respectively. Although both interventions (SI and MI) showed tendency to reduce frequency of FI among patients, but this evidence is weak considering that it was a pilot study that focused on feasibility, acceptability, and adherence to the educational intervention, instead of reduction of FI.

Key: TPNS = Transcutaneous Posterior Tibial Nerve Stimulation; SI = Single Educational Training Intervention; MI Multiple Educational Training Interventions

Secondary outcomes

Reports of behaviours related to FI and dementia

We did not find any reports relating to FI and dementia as outcome measures (Appendix 12).

Adverse effects relating to interventions

The four included studies did not report on adverse effects of their interventions.

Condition-specific quality of life scores

The four included studies did not include any condition-specific quality of life scores.

Measures of psychological well-being

None of the included studies measured this outcome.

Health economic outcomes

No eligible studies were identified for this outcome.

Drug management versus no intervention/placebo/sham/care as usual

No eligible studies were identified for this comparison.

One conservative management versus another conservative management

One study, Blekken 2015 compared conservative management with another conservative management. In Blekken 2015, the authors compared SI comprised of one 7-hour educational meeting with MI, which comprised of two more elements: recruitment of a local opinion leader and educational outreach visits (please see details in Characteristics of included studies).

One conservative management versus drugs: No eligible studies were identified for this comparison.

Surgical management versus no intervention/placebo/sham/ care as usual: No eligible studies were identified for this comparison.

One surgical management versus another surgical management: No eligible studies were identified for this comparison.

One conservative management versus surgical management: No eligible studies were identified for this comparison.

Any containment strategy compared with any other intervention: No eligible studies were identified for this comparison.

3.9 Discussions

Summary of main results

The four included studies focused on conservative management versus care as usual (e.g., where care staff checked residents for incontinence and provided care when the resident was found to be incontinent). None of the four studies presented data which could be quantitatively analysed in RevMan. The four conservative management included:

Functional incidental training (endurance and strength) vs care as usual: In a randomised controlled trial with blinded assessment to examine clinical outcomes and describe the staffing requirements of an incontinence and exercise intervention, the authors reported that incontinence care and exercise intervention resulted in significant improvement for most residents, and most residents who could be reliably interviewed expressed a preference for such care (Schnelle 2002). The authors also reported that the endurance and strength training intervention reduced frequency of FI from 7% of pad checks at baseline to 3% after 32 weeks of intervention, as compared with 6% at baseline to 7% after 32 weeks in the care as usual group (Schnelle 2002). In the same study, the authors reported that incontinence care consumed an average of approximately 7 minutes per resident per episode of care, and the average travel time to locate residents was 3.4 minutes per resident per episode of care. The exercise portion of the episode accounted for the remaining 10.3 minutes per episode. Resident refusal and participation in a social activity were the primary reasons that the functional incidental training (FIT) was not performed completely on any particular day (Schnelle 2002). No data were provided that were suitable for analysis in RevMan.

Multicomponent (Physical activity and mobility endurance, and food and fluid intake) vs care as usual: A randomised control trial to evaluate effects of a multi-component interventions (combined prompted voiding, exercise, and increased food and fluid intake) on FI and UI outcomes reported that the multicomponent interventions significantly increased physical activity, frequency of toileting, and food and fluid intake (Schnelle 2010). In the study, UI improved (P=0.049), as did frequency of bowel movements (P<0.001) and percentage of bowel movements in the toilet (P<0.001). However, the authors reported that the interventions did not change the frequency of FI episodes (Schnelle 2010). They also reported that treatment with subjects with lower MMSE scores (greater cognitive impairment) responded better to treatment (Schnelle 2010). No data were provided that were suitable for analysis in RevMan.

Twelve 30 minutes sessions of TPTNS vs Sham/placebo: In a pilot randomised single-blinded, placebo-controlled trial to assess preliminary effects of a programme of transcutaneous posterior tibial nerve stimulation (TPTNS) on lower urinary tract symptoms (LUTS) and number of episodes of urinary and faecal incontinence in older adults in residential care homes, it was reported that bowel urgency improved in 27% of the TPTNS group compared with 8% of the sham group (P > 0.302), faecal leakage improved in 47% of the TPTNS group compared with 23% of the sham group (P>0.106); however, these differences were not statistically significant (Booth 2013). No data were provided that were suitable for analysis in RevMan.

Staff educational training (single educational training and multiple educational training vs care as usual: In a pilot clustered randomised control study of educational programmes: single intervention (SI) and multiple interventions (MI), the researchers focused on the care home staff and reported that a single educational intervention with one workshop is not sufficient as an implementation strategy to reduce FI, but rather a multifaceted education intervention (workshops, recruitment of opinion leaders, involvement of educational outreach groups, etc) was needed (Blekken 2015). The distribution of continence scores among patients with FI (measured using interRAI H3 Bowel Continence Score) was reported as follows: 12% at baseline compared with 10% at follow-up, with a mean difference -0.03 (SD=1.32) in the SI group; 9% at baseline compared with 8% at follow-up, with a mean difference -0.37 (SD=0.92) in the MI group; and 14% at baseline compared with 16% at follow-up, with mean difference 0.57 (SD=1.15) in the control group respectively (Blekken 2015). Therefore, both interventions (SI and MI) showed tendency to reduce frequency of FI among patients, but this evidence is weak considering that this was a pilot study that focused on feasibility. acceptability, and adherence to the educational intervention, instead of reduction of FI. No data were provided that were suitable for analysis in RevMan.

Overall completeness and applicability of evidence

This review includes no evidence on interventions that are reported to result in reduced FI episodes among older people living in care homes. Based on the results (together with expert opinions from reviewers), there are indications are indications that interventions to reduce FI episodes need to be multifaceted. However, the exact component of such intervention requires further research.

Quality of the evidence

Overall, we found very limited evidence that any intervention that reduces episode of FI in care home residents. We did not perform a GRADE assessment because the data from the included studies were not suitable for comparison. The studies included small sample sizes, selective reporting, and other bias.

Potential biases in the review process

One of the review authors (CN) was also a co-author on two of the included studies (Blekken 2015 and Booth 2013) and two other review authors (AV and LB) were also authors on one of the included studies (Blekken 2015). Nevertheless, we conducted the review according to Cochrane's standard methodology and made attempts to minimise bias in the process.

Agreements and disagreements with other studies or reviews

We have found no other similar reviews. One realist review highlights that while dementia is a documented risk factor for faecal incontinence, studies have failed to address how a person's dementia can affect his/her ability to benefit from bowel care intervention (Goodman 2017). The review suggests consideration of an older person's dementia status when providing bowel care (Goodman 2017). Our four included studies did not report on how the care home residents with dementia benefited from the interventions.

Authors’ conclusions

Implications for practice

This review has no high-quality, trial-based evidence that can usefully inform prevention and/or management of faecal incontinence among older people living in care homes. The included studies reported FI in insufficient detail and did not report conclusive results. None of the studies are comparable, with insufficient participants to infer generalisation of findings and/or provide long-term follow-up to generate robust data to identify clinically important differences in complications, cure rates, or adverse events after the different interventions. In view of the absence of comparative randomised trials on the prevention and/or management options for FI among older people in care homes, care providers need to rely on identification of the underlying cause of FI in a care home resident, his/her functional abilities (e.g., ability to walk to a toilet facility), and the care home environment (e.g., whether there are signage for toilet facilities) when aiming to address FI. Potential treatment or management options for FI among this subgroup of the population which needs to be evaluated include conservative management options (e.g., staff education to heighten awareness of FI and the potential for cure or reduction in FI frequency episodes, measures to improve functional abilities such as walking to a toilet facility, review of side effects of medication a resident is taking, etc.). Any intervention to address FI in this subgroup of the population is likely to have multiple components to address the various underlying factors contributing to the condition.

Implications for research

This review has not satisfactorily addressed any of the pre-stated objectives because of the absence of high-quality, trial-based evidence on treatment or management of FI among older people living in care homes, lack of standardised definition of FI, and methodological differences in how FI is measured and reported. This implies the need for much more robust and well-designed RCTs that compare interventions to cure or reduce FI frequency episodes. Such trials should attempt to randomise residents with FI and clearly describe FI at baseline and after interventions, the effect of confounding factors (if any), and the trials need to be adequately powered. Additionally, trials need to report the effectiveness of alternative management strategies, and their comparative costs and cost-effectiveness (which is currently lacking).

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MKM: Independently examined titles and abstracts of all eligible studies derived from database search, assessed eligibility of the full papers, collected data, independently assessed the risk of bias of included studies using Cochrane's Risk of Bias tool, and developed the review. AV: Independently examined titles and abstracts of all eligible studies derived from database search, assessed eligibility of the full papers, collected data, reviewed, and revised the review.
LB: Independently assessed the risk of bias of included studies using Cochrane's Risk of Bias tool and reviewed and revised the review.
RH: Resolved disagreements concerning eligibility of full papers,
reviewed and revised the review. CG: Resolved disagreements
concerning eligibility of full papers, reviewed and revised the review.
DB: Reviewed and revised the review.
CN: Independently examined titles and abstracts of all eligible studies derived from database search, assessed eligibility of the full papers, collected data, independently assessed the risk of bias of included studies using Cochrane's Risk of Bias tool, and developed the review.

DECLARATIONS OF INTEREST

In accordance with Cochrane's Commercial Sponsorship Policy, the following declarations are applicable for the three years prior to the publication date of this review.
MKM: None
AV: None
LB: None
RH: None
CG: None

PART TWO

Part-2 consists of three chapters (Chapters 4, 5 and 6) that set out the methodological structure (and methods) and the theoretical contexts for the thesis. It also sets out to test the theories using realist evaluation approaches.

Chapter 4: Methodology and overall study design

The aim of this chapter is to explain the philosophical underpinning of this thesis. The chapter presents the methodology and overall research study design of this thesis. The chapter also layout the research methods that are operationalised in Chapter 6. The overall rationale for the study and the research questions that have been addressed in the thesis is presented. This set the scene to conceptualise how three evidence sources – a previously published programme theories (Goodman et al., 2017) and findings from the two systematic reviews (Musa et al. 2019; Musa et al. [submitted]) – were brought together to develop an evidence-based, theory-driven bowel care intervention. The linkages between the evidence sources are provided in Figure 4.1, which depicts the working process for the thesis. Although the figure seems to give an impression of a linear process, this was not the case. It involved iterative process of working collaboratively with the care home stakeholders (Chapter 6).

The research study undertaken in this thesis is a complex intervention study as defined by the UK Medical Research Council (Craig et al., 2008). Therefore, a background of the methodology of complex intervention development and how this PhD research study fits within such framework is subsequently provided. This is achieved by explicating known strengths and limitations associated with complex interventions design. First, the chapter begins by setting out the philosophical background of research study in general, and then focuses more specifically on the philosophical basis of the study undertaken in this thesis.

4.1 Research philosophy

A research philosophy is what the researcher perceives to be truth, reality, and knowledge (Saunders et al., 2015). It outlines the beliefs and values that guide the design of and the collection and analysis of data about a phenomenon in a research study (Ryan and Sfar-Gandoura, 2018). The overarching research philosophy of this thesis stems from scientific realism, as discussed below.

4.2 Research theories

A theory is a statement of relations among concepts within a set of boundary assumptions and constraints (Hassan and Lowry, 2015). They are made coherent by the way in which the propositions are related (Risjord, 2019). Theories are central to scientific understanding because they articulate an understanding that gets behind the observed patterns and explains them (Collins and Stockton, 2018). Theories permit researchers to see relationships among phenomena that might otherwise seem disconnected (Hassan and Lowry, 2015, Risjord, 2019). Without theory, one can never understand the general underlying mechanisms that operate in many guises in different situations (Im, 2018). However, although a theory is important in guiding researchers in many ways, it may sometimes be completely wrong (Davidoff et al., 2015). Nevertheless, theories are a crucial starting point for intervention development, and using evaluation to test and refine the theories is vital for maximising their contribution to a broader evidence-base (Moore and Evans, 2017). The theory employed in this thesis is called 'programmed theory' (please see below for details of programme theories).

4.3 Research paradigms

A paradigm constitutes four categories of interrelated views that underpin concepts of knowledge and knowing: *ontology* – one's understanding of the nature of reality and what can be known about that reality; *epistemology* (from the Greek word *epistêmê* meaning 'knowledge') – understanding of the nature of knowledge, the 'getting to know' process, the relationship between the person who seeks to know and the knowledge they construct, and the criteria for making claims about knowledge (Haigh et al., 2019, Krauss, 2005); *methodology* – approach to the construction of knowledge; and *axiology* – the influence of values on knowledge that is acquired and how it is acquired. A coherent set of views in relation to these four considerations constitute a paradigm position (Haigh et al., 2019). Epistemology is driven by the nature of the underlying ontology and in turn, drives the methodology of investigations (Haigh et al., 2019).

Different disciplines have developed traditions in relation to the aforementioned views about research paradigms. For example, medical sciences have tended to adopt a positivist paradigm, based on the view that what is real, and therefore knowable, is what can be observed ‘out there’ and measured. In contrast, social sciences have often adopted a social constructivist paradigm which rests on the view that what is real is what our individual minds ‘make’ real to us; reality is a construction – by and of the mind (Haigh et al., 2019).

4.4 Positivism, constructivism, and realism

There are three commonly cited philosophical research paradigms in health and social sciences to guide research methods and analysis: positivism (sometimes called scientific), constructivism (or interpretivism) and critical theory (realism) (Ryan and Sfar-Gandoura, 2018).

Positivists aim to discover what exists through prediction and control using mainly quantitative methods with the researcher being an independent observer (Lincoln and Guba, 2000). In the positivist paradigm, knowledge is discovered and verified through direct observations or measurements of phenomena; facts are established by taking apart a phenomenon to examine its component parts (Krauss, 2005). The positivists believe in empiricism, the idea that observation and measurement are at the core of the scientific endeavour (Krauss, 2005). A positivist might describe science as the methodical observation of phenomena which enables the observer to identify the causal relationships that exist between those phenomena (Porter, 2001). Positivists share the common goal of generalisation (Lincoln and Guba, 2000), but because social sciences involve complex human behaviours (some of which are unpredictable) (Fenneman and Frankenhuis, 2020, Zavada, 2013), positivists findings may fail to demonstrate generalisability (Bhaskar, 1979, Bhaskar, 1989). In nursing and healthcare practice, positivist research may predict outcomes of an intervention (e.g., that ‘intentional rounding’ in acute hospital prevents pressure ulcers and falls among patients) (Di Massimo et al., 2022), but the challenge is in transferring to situations of complexity (Williams et al., 2017). For example, implementing intentional rounding on a busy ward withing a hospital environment may be a challenge, or even impossible due to staffing level (e.g., lack of allocated time to care) (Harris et al., 2019b, Sims et al., 2020).

In contrast to the positivists' stance, constructivists are more interested in investigating qualitative differences in the meanings people give to experiences (Graham and McAleer, 2018). The constructivist view is that knowledge is established through the meanings attached to the phenomena studied; researchers interact with the subjects of study to obtain data; and knowledge is context and time dependent (Krauss, 2005). Constructivists argue that truth and knowledge are culturally and historically situated, based on people's experiences and their understanding of them (Bergin et al., 2008). They argue that there is no reality which can be used as a standard, and that there are many truths which are equally true even if they are contradictory (Kazi, 2003). Constructivists suggest that researchers can never be completely separate from their own values and beliefs, and that those values and beliefs will inevitably inform the way in which they collect, interpret and analyse data (Ryan and Sfar-Gandoura, 2018).

Realism is a methodological paradigm, rooted in philosophy, which positions itself between positivism (the world is real and can be observed directly) and constructivism (given that all we know has been processed through the human mind, we can never be sure exactly what reality is) (Jagosh et al., 2014, Pawson, 2006a, Pawson, 2013). Realism asserts that both the material and the social worlds are 'real', at least in the sense that anything that can have real effects is itself real (Westhorp, 2014). This has two main implications for programme evaluation. Firstly, it implies that programmes and policies are also 'real' and can have real effects – positive and negative, intended, and unintended. Secondly, it implies that social institutions and constructs (culture, class, gender, religion, political and economic systems) will have real effects on whether and how programmes work (Westhrop, 2018).

Realism, as a philosophical paradigm, has elements of both positivism and constructivism (Williams et al., 2017). For this reason, this thesis adopted realism as a philosophical paradigm. Realism is also known as *critical realism* (Hunt, 1991), *post-positivism* (Guba and Lincoln, 1994) or *neopostpositivism* (Manicas and Secord, 1983). Realism concerns multiple perceptions about a single, mind-independent reality (Krauss, 2005). Rather than being supposedly value-free, as in positivist research, or value-laden as in interpretive research (Guba and Lincoln, 1994), realism is instead value cognizant; conscious of the values of human systems and of researchers (Krauss, 2005).

4.4.1 Philosophical foundation of critical realism

Critical realism has its philosophical foundation in the work of British philosopher, Roy Bhaskar (Bhaskar, 1989), who differentiated between the real (what exists and how it might behave), the actual (what actually happens), and the empirical (our knowledge and experiences of what happens), thus raising the paradox that our knowledge of the natural world is inescapably socially constructed (Ellaway et al., 2020). Bhaskar called this transcendental realism (Wynn and Williams, 2012). Bhaskar's original work has been refined and extended by himself and a number of authors (Bhaskar, 1989, Danermark et al., 2002), the scope of which will not be detailed here.

Ontologically, critical realism reflects a postpositivist perspective that the social world is real and independent of our knowledge of it and that it is driven by mechanisms (Ellaway et al., 2020). Critical realism attempts to answer the question 'what must reality be like to make science possible?' (Eastwood et al., 2014). A central aspect of critical realism ontology is the distinction between three ontological domains: the empirical, the actual and the real. The empirical domain comprises of our experiences of what actually happens (e.g., experiences) and the actual is constituted by the things that happened independently of whether we observed them or not (i.e. events) (Eastwood et al., 2014).

Critical realism offers an alternative position that neither rejects nor endorses the different stances offered by the positivist and constructivist paradigms, but offers a different approach to understanding reality (Williams et al., 2017). It provides researchers with novel opportunities to explore and/or investigate complex organisational occurrences in a holistic way (Easton, 2010). The use of critical realism helps to provide a rich and reliable explanation of patterns of events through the development of appropriate accounts of the causal powers, entities and mechanisms which created them (Martin, 2016). Critical realism has been endorsed by a range of disciplines, especially in research which focuses on real problems and acknowledges the complexities of the social world (Clark et al., 2007, Dugle et al., 2020, Frederiksen and Kringelum, 2021, Haigh et al., 2019, Wilkinson et al., 2021). In recent evidence from healthcare literature, there has been a surge in research using realist methodology (realist evaluation and realist synthesis), which is underpinned by the philosophy of critical realism and which offers a different perspective to understanding nursing and healthcare problems through the realist lens (Browne et al., 2021, Chadborn et al., 2019, Clark et al., 2007, Devi et al., 2021, Flynn et al., 2019, Goodman et al., 2017, Spacey et al., 2021).

The most notable attempt to develop critical realism as an approach to evidence synthesis using Bhasker's work has been the RAMESES project, which has published quality guidelines for realist reviews (Wong et al., 2014). However, Ray Pawson (Pawson, 2013) has been critical of Bhaskar's work, the debate of which is beyond the scope of this thesis. Significant to this thesis is Pawson's establishment of the realist evaluation (Pawson and Tilley, 1997, Pawson and Tilley, 2004), which is operationalised in this thesis (see Chapter 6). Realist evaluation is being promoted by the RAMESES project (Wong et al., 2016). The RAMESES project writes guidelines on realist approaches and runs training events and conferences promoting its approach to synthesis and evaluation.

4.5 Pawson and Tilley's approach to 'realist evaluation'

In their seminal work, Pawson and Tilley (1997) describe realist evaluation as an explanation-driven, generic approach to evaluation of research evidence grounded in scientific realism. The goal of scientific realism is to examine regular patterns that exist within reality and offer a more comprehensive understanding of these patterns by providing in-depth explanations through the exploration of generative causal mechanisms, which are sensitive to contextual and social influences (Kazi, 2003, Marchal et al., 2012, Salter and Kothari, 2014).

Realist evaluation (RE) (Pawson and Tilley, 1997) represents a theory-driven evaluation methodology, which has been widely used by researchers in the field of nursing and healthcare policies (Dalkin et al., 2015, Graham and McAleer, 2018, Jackson and Kolla, 2012, Rycroft-Malone et al., 2016). In the context of modern nursing practice that is embedded within complex social situations, a realist research approach has been preferred because it focuses on real problems and acknowledges the complexities of the social world, which otherwise would not be achieved by positivist or constructivist approaches (Williams et al., 2017). Application of the principles of realist evaluation in this study is detailed under research design and methods (below).

To understand the different philosophical research concepts, it is important to understand how theories and conclusions are found in the data – that is, the reasoning applied to data to obtain the outcomes. Some of these reasonings include inductive, deductive, abductive, and retroductive reasoning.

4.6 Types of reasoning

4.6.1 Inductive reasoning

Inductive reasoning starts with observation, experiment and measurement, and generalisation and finding patterns in data; theory is then developed to describe the situation (Bryman 2008). In other words, induction is to generate theory from evidence (i.e. studying one or many cases to generate generalised theories) (Jagosh, 2020).

4.6.2 Deductive reasoning

Deductive reasoning follows the reverse process: find a theory, make predictions based on the theory, and then use observation or experiment to test it (Bryman 2008). Deductive reasoning is used to postulate theories that can be tested against the evidence (e.g., testing generalised expectations against specific cases) (Jagosh, 2020). Based on the results of studies, there may be an understanding that a theory does not fit the facts well and so the theory must be revised to better predict reality. Data analysis in the stakeholders' engagement (realist evaluation – Chapter 6) adopted this type of reasoning because there was existing theory (programme theories) – see Chapter 5.

4.6.3 Abductive reasoning

Abduction is being able to understand a phenomenon in a new way by observing and interpreting this phenomenon in a new conceptual framework (Danermark et al., 2019). It is a creative reframing of a phenomenon of interest into a conceptualisation that leads inquirers to explore the empirical world in new and innovative ways (Jagosh, 2020). Thus, abductive reasoning is gut feeling, hunch or informed imagination that leads to new ideas for generating theories and testing possible mechanisms (Jagosh, 2020). Abduction does not move directly from empirical observations to theoretical inferences, as is the case in purely inductive research, but relies heavily on theories as mediators for deriving explanations (Modell, 2009).

4.6.4 Retroductive reasoning

Retroduction is a form of inference that seeks to theorise and test hidden mechanisms (Jagosh, 2020). In addition to identifying and verifying causal mechanisms (abduction), retroduction allows the researcher to 'identify the necessary contextual conditions for a particular causal mechanism to take effect and to result in the empirical trends observed' (Fletcher, 2017: 189). Retroduction is an explanatory approach characterised by the use of causal mechanisms as the basis for this explanation, the possibility for multiple potential explanations, and the understanding that these causal mechanisms may or may not be observable empirically (Wye et al., 2014). Data analysis in the realist evaluation operationalised this type of reasoning (please see Chapter 6).

4.7 Critical analysis of methodology

The research methodology of the thesis is grounded in complex healthcare intervention development, as defined by the UK Medical Research Council (MRC) guidance for developing and evaluating complex interventions (Medical Research Council (MRC), 2000),as first revised in 2008 (Craig et al., 2008), and subsequently in 2021 (Skivington et al., 2021). Complex intervention research can take an efficacy, effectiveness, theory based, and/or systems perspective, the choice of which is based on what is known already and what further evidence would add most to knowledge (Skivington et al., 2021).

This chapter presents both overall methodology of the thesis and the methods used for realist evaluation (Chapter 6). The methods used for the feasibility study are not presented here but in Chapters 7 and 8 respectively. Figure 4.1 presents the working structural process, showing triangulation of evidence from three evidence sources: two systematic reviews undertaken by the PhD candidate, and a publicly available realist programme theories (the FINCH programme theories) – which is tested in a realist evaluation in Chapter

6. The six steps approach in ‘intervention mapping’ (Bartholomew-Eldredge et al., 2016, Hurley et al., 2016) (please see full details of intervention mapping in Chapter 7) helped to combine the evidence with theories to develop a bowel care intervention in this thesis.

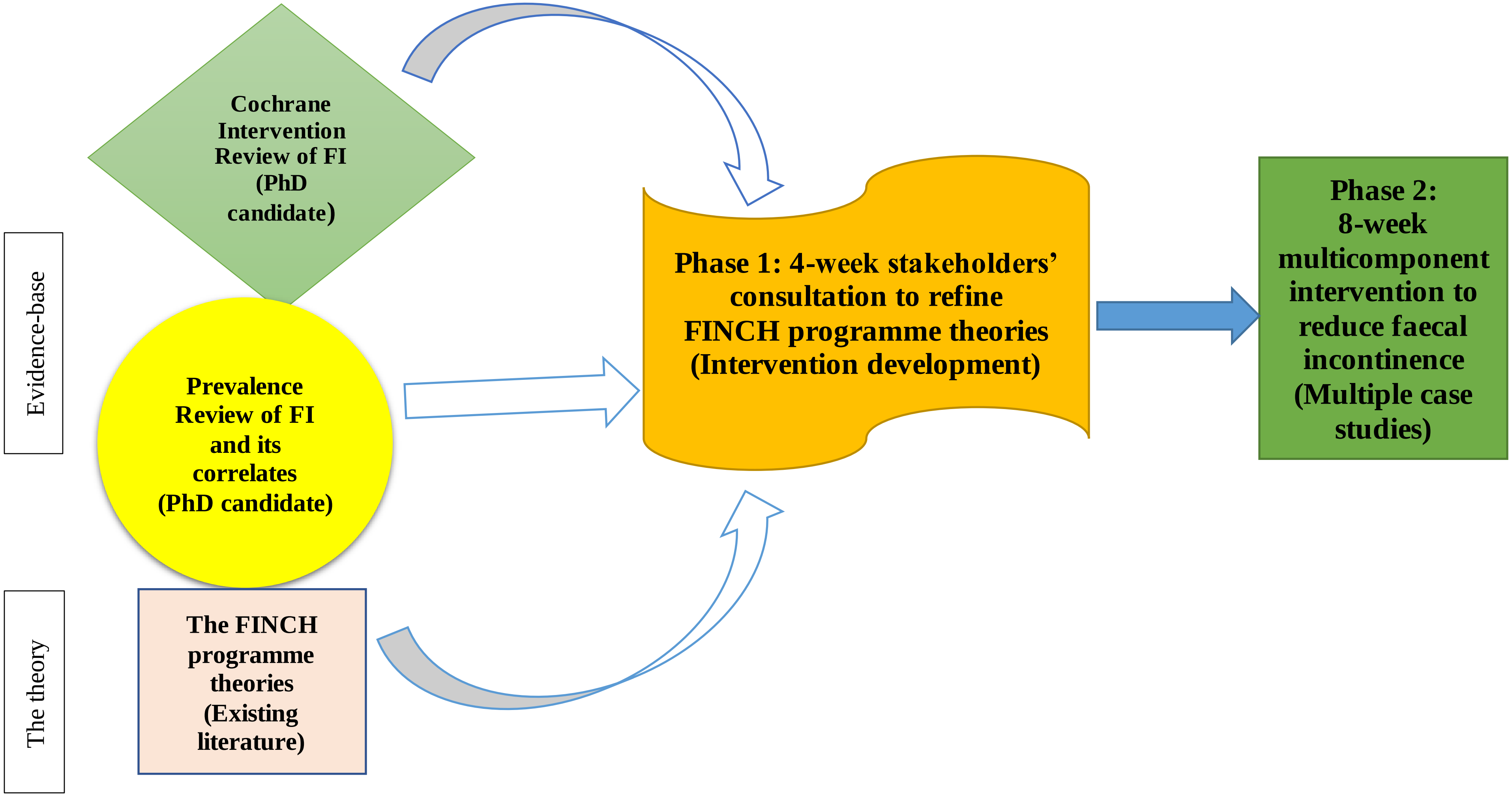


Figure 4.1: Thesis working structural process showing triangulation of evidence from three evidence sources

4.8 Significance of the study

Faecal incontinence (FI) is a debilitating health condition, with high prevalence among older people living in care homes (Akpan et al., 2007, Blekken et al., 2016, Chassagne et al., 1999). The medians for prevalence (as reported by the studies) of isolated faecal incontinence (faecal incontinence with no urinary incontinence), double incontinence (the presence of faecal plus urinary incontinence), and all faecal incontinence (anyone with faecal incontinence, whether isolated or double) were 3.5%], 47.1%, and 42.8%, respectively (Musa et al. 2019). The current FI prevalence rate among older people in general, and particularly those living in care homes, is projected to raise with noticeable aging population (ONS, 2016). Meanwhile, there is currently no evidence-based intervention that reduces the frequency of FI episodes among older people living with dementia in care homes [PhD Paper 2].

It is important for care workers working in care homes to consider not only the physical assistance that can be provided to a resident with FI, but also to offer emotional support to such residents (Bucher, 2020). This requires the care home workforce providing continence care to be knowledgeable, and able to implement current guidelines and evidence-based practice in the care of the older people with FI, especially those living with dementia. Promoting continence care in care homes is complex, and currently there is a dearth of evidence on the most effective intervention in managing and reducing FI in this setting (Goodman et al., 2017). The use of incontinence pads is the most widely option for managing FI. In one study, approximately 80% of the care home residents used incontinence pads (Blekken et al., 2016). However, incontinence pads do not contain odour (and protect the skin from faeces) and therefore do not preserve residents’ dignity. Additionally, incontinence pads are expensive and cause financial burden to the residents, residents’ family, and the care homes. Continence care impacts workforce morale and staff turnover because naturally people do not like to touch someone else’s faeces.

Therefore, the prevalence of FI in care homes, its consequences, vis-à-vis the economic impact of the condition (both personal and institutional costs) justifies the need to understand and to devise achievable, cost-effective, evidence-based quality care intervention strategies. Evidence suggests that an intervention that is based on relationship-centred care may ameliorate FI among residents in care homes (Norton et al., 2010, Norton et al., 2014). Effective continence care can save valuable healthcare resources and it can improve quality of life as well as improve dignity in people.

The overall aim of this research study is to develop and test feasibility of a well-defined multicomponent intervention that is theory-driven, which includes toileting, physical exercises, food and fluid intakes, medications review, and staff education in bowel care, and whether there are indications that the intervention may reduce FI among care home residents. It is envisaged that this study will act as a guide for potential future research, assessing whether it may be possible to deliver a further larger study. It is also envisaged that the results will be useful to residents in care homes, their relatives, caregivers, providers of care homes and care home policy makers.

4.9 Research questions

The overall research questions for this study are: (1) is it feasible to develop a faecal incontinence care intervention for older people aged 65 years and above living with dementia in care homes? (2) can the intervention lead to a reduction in frequency of faecal incontinence episodes among the care home residents? To address these feasibility and efficacy questions, the study will address:

- Whether the proposed intervention is acceptable to the care home staff that deliver bowel care.
- The facilitators and/or barriers to delivering bowel care intervention in the care home setting.
- Whether the proposed intervention can reduce episodes of faecal incontinence.

4.10 Methodological rigour in intervention development

It is generally acknowledged when assessing the effectiveness of healthcare interventions that the most highly regarded research method is the randomised controlled trial (RCT) (Feneck, 2007, Rothwell, 2005). The RCT is considered a gold standard study design because it is a comparative study whereby participants are randomly allocated to two groups: one of the groups receives standard care or placebo (the control group); the other group receives the intervention (the intervention group). The groups are then compared in terms of the outcome of interest, with relevant differences attributed to the impact of the intervention (Blackwood et al., 2010). Its power to standardise conditions, exert control over extraneous factors and reduce bias is seen as the epitome of good practice. RCTs are generally placed at the top of the hierarchy of evidence, while various forms of observational studies are placed beneath it (Harbour and Miller, 2001).

However, the RCT has its limitations. Michael Rawlins, Chairman of the National Institute for Health and Clinical Excellence (NICE) calls the attempt to place evidence in hierarchies 'illusory' and the placement of RCTs at the top of hierarchy of evidence as an 'undeserved pedestal' (Rawlins, 2008). The RCT is criticised for not being able to uncover what is really happening underneath the surface of events to enable findings to be replicated or even translated to 'real' practice (Moore et al., 2015). RCTs are good for providing evidence about the effects of an intervention, but they do not provide insight into the reasons why an intervention is effective (or not) (van Meijel et al., 2004). The effects of interventions are usually very dependent upon factors such as the characteristics of participants, the setting for the intervention, and the way in which the research is implemented (Blackwood et al., 2010). There is little evidence to support that the results of RCTs can be reliably extrapolated to the care of patients in general (Rothwell, 2005, van Meijel et al., 2004). One potential explanation for this is the Hawthorne effect, a term that describes research outcomes that may have resulted not because of changes in the experimental parameters or stimulus, but an inclination of the subjects of an experimental study to change or improve the behaviour being evaluated during study period (Cherry, 2018).

In evidence-based nursing practice, greater reliability in successfully achieving the desired results of the intervention depends on more than empirical research findings of studies such as RCTs (Fletcher et al., 2016). Also paramount to evidence-based practice nursing (and other health and social care research) are understanding of the processes that are responsible for the results of empirical research findings and the limitations of putting such findings into practice successfully (Blackwood et al., 2010). In health and social care research, a number of factors may influence the effectiveness of an intervention: how it was introduced, implemented and delivered (Fletcher et al., 2016); who undertook the intervention; who received it; whether or not the 'system' was set up to enable its smooth operation; or if the wider 'system' (funding or policy) was enabling and supportive (Blackwood et al. 2010).

Evidence-based nursing practice is underpinned by complex interventions. Complex interventions are defined as interventions with several interacting components that impact the length and complexity of the causal chain from intervention to outcome and the influence of features of the local context (Craig et al., 2008). The feasibility study in this thesis can be described as a complex intervention study because it has interacting components (e.g., toileting exercise, dietary and fluid intake, staff education, and medication review), with mixed methods approach to unravel the chain from intervention to outcome (see Chapter 7). In complex intervention studies in health and social care, preventing some of those weaknesses in doing RCTs as mentioned above is challenging. A way forward is to employ a research study design that best answers the research question.

Inappropriate research study design, insufficient attention to previous research results, poor research questions, and inadequate reporting have been cited as contributing factors for an estimated 85% of research waste (Chalmers and Glasziou, 2009, Ioannidis et al., 2014). Evidence suggests that even though the significance of methodological rigour at the early stages of intervention development had previously been acknowledged (Craig et al., 2008), research wastes continue because many developed healthcare interventions have little or no impact on healthcare (Chalmers et al., 2014). Much healthcare research continues to be wasted because findings are inappropriate for patients (Chalmers and Glasziou, 2009), not efficacious after the trial stage (Glasgow et al., 2012), or impossible to replicate (Resnick, 2018).

The potential explanations for continued research waste include: inadequate use of intervention development frameworks, lack of theory-driven interventions (De Silva et al., 2014, Michie et al., 2011, O'Cathain et al., 2019), limited understanding of causal mechanisms that make interventions work (or fail) (Moore et al., 2015, Pawson and Tilley, 1997), and inadequate reporting of intervention development (Bleijenberg et al., 2018, Möhler et al., 2012).

Some key principles of intervention development are that it is dynamic, iterative, open to change (creative) and forward looking to future evaluation and implementation. Intervention developers are said to likely move backwards and forwards dynamically between overlapping actions within intervention development, such as reviewing evidence, drawing on existing theory and working with stakeholders (O'Cathain et al., 2019). How this PhD research study aims to mitigate against research waste and incorporate iterative process of intervention development is summarised in Table 4.1 below. This is achieved through the six steps approach in intervention mapping (Bartholomew-Eldredge et al., 2016, Hurley et al., 2016) (please see full details of the intervention mapping approaches in Chapter 7).

Table 4.1: Proposed resolutions of issues relating to methodological rigour

Problem	Solution
Inadequate use of intervention development frameworks	Use of the MRC Framework for developing complex interventions (Skivington et al., 2021)
Inattention to previous research results	Systematic literature reviews: (1) Prevalence Review (2) Intervention Review
Lack of theory-driven interventions	Use of programme theories proposed by the FINCH Study (Goodman et al., 2017).
Limited understanding of causal mechanisms that make interventions work (or fail)	Use of realists' framework: context-mechanism-outcome (CMO) configuration (Goodman et al., 2017, Jackson and Kolla, 2012, Pawson and Tilley, 1997, Wong et al., 2014).
Inadequate reporting of intervention development	The use of TIDieR (Template for Intervention Description and Replication) checklist and guide (Hoffmann et al., 2014)

4.11 The Medical Research Council Framework for developing complex interventions

The UK Medical Research Council (MRC) guidance on evaluating complex interventions was published in 2000 (Campbell et al., 2000), and revised in 2008 (Craig et al., 2008) and more recently in 2021 (Skivington et al., 2021). The latter was published after the current intervention was developed but is added here for completeness. An intervention might be considered complex because it has a number of interacting components; requires expertise and skills required by those delivering and receiving the intervention (Craig et al., 2008, O'Cathain et al., 2019); or because of the permitted level of flexibility of the intervention or its components (Skivington et al., 2021).

Following the revised MRC guidance in 2008, interest in complex interventions grew rapidly especially in health and social care research. Yet, there remained gaps in the framework such as research priority-setting and the application of complex systems science to health interventions that requires amendment. Taking account of recent developments in theorising and methods, and the need to maximise the efficiency, use, and impact of research, the MRC framework has been revised for the second time, commissioned jointly by the Medical Research Council and the National Institute for Health Research (Skivington et al., 2021).

4.11.1 The first version of the MRC guidance

The first guidance of the MRC framework was published in response to the difficulties encountered by those attempting to develop and evaluate the impact of multicomponent interventions (Datta and Petticrew, 2013, Medical Research Council (MRC), 2000). The first version of the MRC framework (Figure 4.2) is presented in a step-wise approach in five phases: preclinical (or theoretical), modelling, exploratory, definitive RCT, and long term implementation phases (Campbell et al., 2000). The *preclinical or theoretical phase* aims to identify the evidence (e.g., a review of the literature for empirical or theoretical basis) that the intervention might have the desired effect. It enables the investigators to formulate a sound hypothesis, identify potential confounding factors and design issues (Blackwood et al., 2010). The *modelling phase* explores understanding of the components of an intervention (e.g., qualitative testing through focus groups, surveys, and case studies), how the various components fit together and the underlying mechanisms that influence outcomes. The *exploratory phase* is where the information gathered so far is used to develop the intervention and study design (or methodological issues for the main trial), which will then be tested for feasibility of delivery and acceptability to service users and providers. In practice, the recruitment process and the intervention are piloted and based on the results, a *definitive RCT* may then be carried out to evaluate the effectiveness of the intervention. A process evaluation may be carried out as part of the definitive RCT to check that the intervention was delivered as intended and to assess moderators and mediators of any effect, usually with a qualitative element as well (Breitborde et al., 2010). The *long-term implementation* of the intervention in practice is usually carried out after the efficacy RCT (Moore et al., 2015).

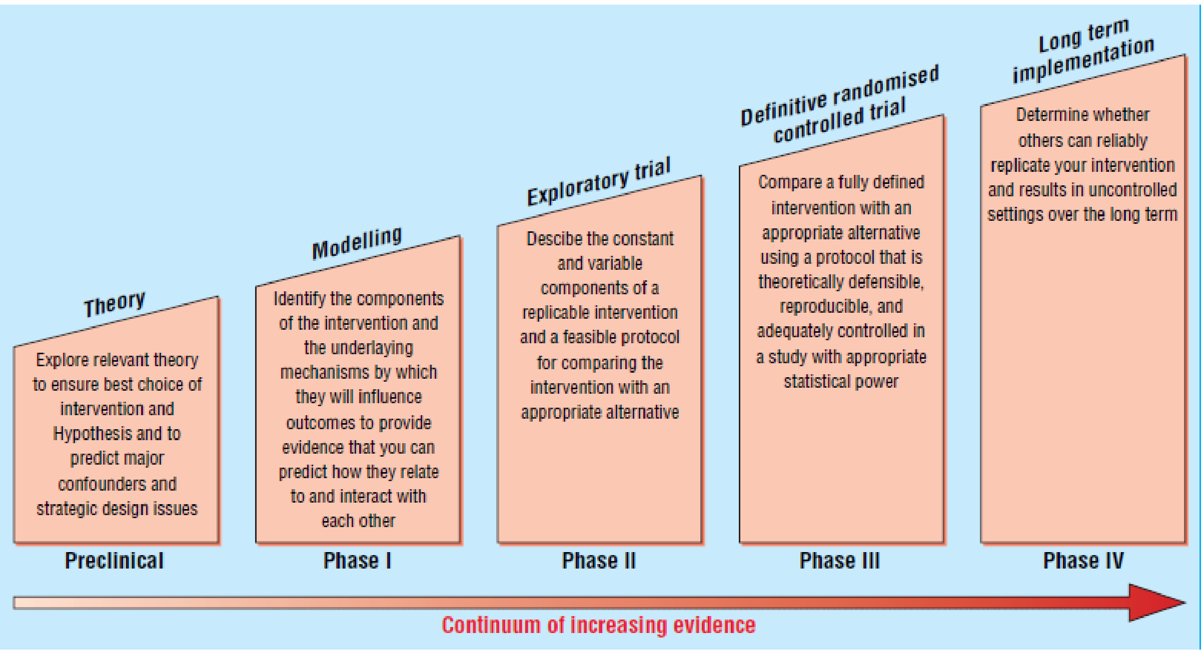


Figure 4.2: First version of the Medical Research Council Framework for the development of complex interventions (Campbell et al. 2000, p. 695)

This first version of the MRC framework (Figure 4.2) became useful to intervention developers, but it was also criticised for lacking details on how to achieve the early stages of intervention development, namely: review of theory and evidence, and modelling (Hardeman et al., 2005), as well as its linearity of process and omission of contextual factors during intervention development (Campbell et al., 2007). Firstly, despite its emphasis on the significance of the preclinical (or theoretical) and modelling phases, the 2000 MRC framework was described as lacking details on how these phases were to be conducted (Hardeman et al., 2005). Secondly, if intervention development were to follow a sequential order as in the step-wise approach offered by the 2000 MRC framework (instead of an iterative approach), it was argued that the model would not conform to complex interventions that involve multiple components and often different methods of inquiry

(Campbell et al., 2007). Campbell and colleagues (2007) argued that understanding the context in which an intervention is delivered is crucial when designing and assessing whether an intervention that is effective in one setting may also work in others.

4.11.2 The second version of the MRC guidance

The UK Medical and Research Council (MRC) published a revised Framework for the Development and Evaluation of RCTs for Complex Interventions to Improve Health to help both researchers and funders to recognise and adopt appropriate research methods to ensure not only the existence of interventions, but also that interventions are accepted and sustained over time (Craig et al., 2008). The framework emphasises development of interventions that are both empirically and theoretically driven in order for the interventions to be effective and efficient (Craig et al., 2008).

Attempting to resolve issues of linearity and the omission of contextual factors associated with the 2000 version of the MRC framework, the revised version goes further by incorporating iterative processes of conducting the first three phases (as indicated by the double arrows in Figure 4.3), as well as proposing supplementing RTCs with other methodological approaches (Blackwood et al., 2010).

The revised MRC Framework contains four elements: development, feasibility/piloting, evaluation, and implementation (Figure 4.3).

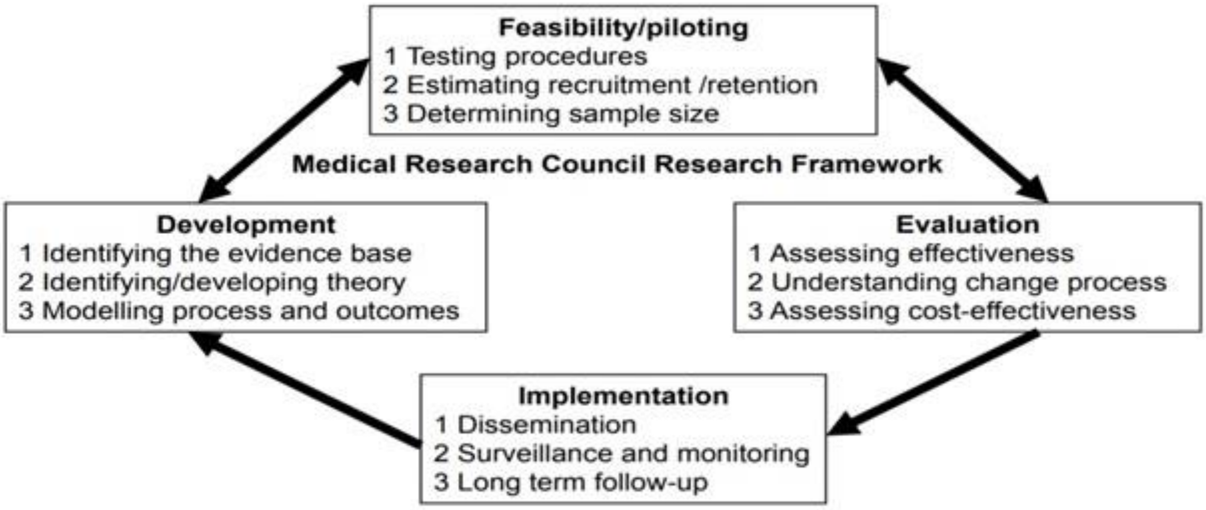


Figure 4.3: The revised MRC Framework for development of complex interventions (Craig et al. 2008, p.8)

From Figure 4.3, the MRC Framework is presented as an iterative approach (Blackwood et al., 2010, Campbell et al., 2007). These iterative cycles involves using mixed-methods research approaches to measure processes and intermediate outcomes, and to assess the acceptability, feasibility, desirability and potential unintended harms of the intervention (O'Cathain et al., 2019). Developers of health and social care interventions have been encouraged to review published research evidence, draw on existing theories, and to involve stakeholders to understand contextual factors, while paying attention to future implementation in the real world when designing and/or refining an intervention (O'Cathain et al., 2019, Owens et al., 2011).

The first phase of the MRC Framework, *intervention development*, involves identification of the evidence-base for the intervention, identification and/or development of theoretical rationale, and modelling components of the intervention (Craig et al., 2008). Identifying the evidence-base for the intervention may require identifying the relevant, existing evidence base, ideally by carrying out a systematic review (if none exists) (Craig et al., 2008). Reviewing published research evidence at the start of intervention development can help to define the health problem and its determinants, understand the context in which the problem exists, clarify the target population of the intervention, identify potential barriers and facilitator to delivering the intervention, and other key uncertainties such as cost-effectiveness (O'Cathain et al., 2019).

Nevertheless, the rationale for an intervention may not be clear from the onset of a research study (e.g., changes to be expected, and how those changes are to be achieved) (O'Cathain et al., 2019). In such cases, the revised MRC Framework recommends intervention developers to draw on existing evidence and theory to develop a theoretical understanding of the likely process of change (Campbell et al., 2007, Chalmers et al., 2014, Craig et al., 2008, O'Cathain et al., 2019). The significance of drawing on existing theories is that theories can help to identify what is important, relevant and feasible to inform the intended goals of the intervention (O'Cathain et al., 2019). An alternative to drawing on existing theories is articulating programme theories at the start of intervention development. A programme theory describes how a specific intervention is expected to lead to its effects and under what conditions (Rogers, 2008). Programme theories are not static, and therefore require testing and refinement throughout the development process using primary and secondary data collection and stakeholder input (O'Cathain et al., 2019).

The revised MRC Framework recommends working with stakeholders when developing and piloting an intervention. The rationale for involving stakeholders from the start, and indeed working closely with them throughout, is that they can help to identify priorities, understand the problem and help find solutions to future implementation failures in the real world (Moore et al., 2015). Modelling an intervention may provide opportunity to examine design issues and components of the intervention to determine what they are, how they fit together, and the mechanism by which they will influence the outcomes (O'Cathain et al., 2019).

The second phase of the MRC Framework, *feasibility/piloting*, involves testing procedures the intervention for acceptability, estimating the likely rates of recruitment and retention of research participants, and the calculation of appropriate sample sizes (Craig et al., 2008). The dichotomy between feasibility and pilot studies remains debated (Lancaster, 2015). Simplistically, feasibility studies may focus only on selected intervention or trial elements about which there is particular uncertainty; whereas, pilot studies may be a smaller version of the main trial (Fletcher et al., 2016).

The *evaluation phase* of the MRC Framework encompasses assessing effectiveness, understanding processes, and assessing cost-effectiveness of the intervention (Campbell et al., 2007, Craig et al., 2008). A crucial aspect of assessing effectiveness of an intervention is underpinned by the research design that best answers the research question. The revised MRC Framework gives choice between experimental designs (e.g., RCTs) and non-experimental designs. An important point for design consideration is the choice of outcome measures. A good theoretical understanding of the intervention, derived from careful development work, is key to choosing suitable outcome measures. (Craig et al., 2008).

Process evaluation can have a vital role in understanding the feasibility of the intervention and optimising its design (Moore et al., 2018). A process evaluation is often highly valuable and helps to provide insight into why an intervention has unanticipated consequences, or why a successful intervention works and how it was delivered (Craig et al., 2008, Carroll et al., 2007). It usually aims to capture fidelity (whether the intervention was delivered as intended) and dose (the quantity of intervention implemented) (Moore et al., 2015). Process evaluation may explore mechanisms of impact of an intervention and how the effects might be replicated in future interventions (Grant et al., 2013a); and how contextual factors affect outcomes (Moore et al. 2015). Ideally, cost-benefit analysis should be taken into account to ensure that the cost of the study is justified by the potential benefit of the intervention (Craig et al., 2008).

The final phase of the MRC Framework, *implementation*, encompasses dissemination of research findings, surveillance and monitoring, and long-term follow-up. The framework admonishes researchers that publication of the research findings is essential, but it is only part of an effective implementation strategy (Craig et al., 2008). It further emphasises the need to use methods that are accessible and convincing to decision-makers when embarking on implementing research findings into routine practice.

4.12 Limitation of the use of the second version of the MRC framework

At the heart of the MRC Framework lies a fundamental ontological contradiction that concerns demonstration of efficacy and efficiency during complex intervention development. Some of the lacunae in the second version of the MRC Framework are considered in this section.

From the MRC framework, it is unclear what should be the focus of healthcare evaluation research (Fletcher et al., 2016). Should it be about the efficacy of the intervention being studied per se, or the contextual factors that promote or inhibit the effectiveness of that intervention, or both? The term efficacy is defined by the Cochrane Collaboration Glossary of Terms as "*the extent to which an intervention produces a beneficial result under ideal conditions*" and effectiveness is defined as "*the extent to which a specific intervention, when used under ordinary circumstances, does what it is intended to do*" (Higgins et al., 2019). Ostensibly, the MRC framework seems to aspire to the latter definition but such an aspiration is difficult to square with its continual acknowledgement of RCTs as gold standard methods (Blackwood et al., 2010).

One main criticism of the second versions of the MRC Framework, therefore, was that it made no mention of considerations of context when discussing intervention development, and only briefly mention the role of contextual factors in modifying intervention effects (Moore and Evans, 2017). This is contrary to the recognition of the vital importance of contextual factors in intervention research more than two decades ago by Pawson and Tilly, who argued that mechanisms of change are always contingent on context; that what "works" in one time and place may be ineffective, or even harmful, elsewhere (Pawson and Tilley, 1997). The contextual consideration is particularly more important to the development of complex interventions because a range of potential influences on the direction and magnitude of intervention effects derives from variant properties of the systems in which an intervention is implemented (Noyes et al., 2013). It has been acknowledged that contextual factors during implementation influence effectiveness and success of an intervention (Moore et al., 2018, O'Cathain et al., 2019).

There are some suggestions on how to combine the MRC framework with other research methodologies such as realist evaluation which emphasises contextual factors for a successful intervention development and implementation (Fletcher et al., 2016). In conformity with such a recommendation, this PhD research project consulted with care home stakeholders during intervention development phase, and it subsequently employed realist approaches as detailed in *Chapter 6.*

4.13 The third version of the MRC guidance

The previous framework and guidance of the MRC framework were criticised for being based on a paradigm in which the salient question was to identify whether an intervention was effective. Critics believed that complex intervention research driven primarily by this question could fail to deliver even if the interventions were implementable, cost effective, transferable, and scalable in real world conditions. The major criticism was that the previous MRC framework did not prioritise the contextual factors that were relevant when developing an intervention.

Therefore, to deliver solutions for real world practice, the third version of the MRC guidance advocates strong and early engagement with patients, practitioners, and policy makers, shifting the focus from the "binary question of effectiveness" to whether and how the intervention will be acceptable, implementable, cost effective, scalable, and transferable across contexts (Skivington et al., 2021). The new framework, therefore, takes a pluralistic approach and identifies four perspectives that can be used to guide the design and conduct of complex intervention research: efficacy, effectiveness, theory based, and systems (Table 4.2). Using a vaccination study as an example, Skivington and colleagues demonstrate how each of the four perspectives can enable development of a research design and conduct of complex intervention research studies (Table 4.2).

Table 4.2: Research perspectives

Perspective and research question	Key points	Vaccine study example
Efficacy		
To what extent does the intervention produce the intended outcomes in experimental or ideal settings?	Conducted under idealised conditions; maximises internal validity to provide a precise, unbiased estimate of efficacy	Seeks to measure the effect of the vaccine on immune system response and report its safety.
Effectiveness		
To what extent does the intervention produce the intended outcomes in real world settings?	Intervention often compared against treatment as usual; results inform choices between an established and a novel approach to achieving the desired outcome	Seeks to determine whether the vaccination programme, implemented in a range of real-world populations and settings, is effective in terms of what it set out to do (e.g., prevent disease)
Theory based		
What works in which circumstances and how?	Aims to understand how change is brought about, including the interplay of mechanisms and context; can lead to refinement of theory	Asks why effectiveness varies across contexts, and asks what this variation indicates about the conditions for a successful vaccination programme.
Systems		
How do the system and intervention adapt to one another?	Treats the intervention as a disruption to a complex system	Seeks to understand the dynamic interdependence of vaccination rollout, population risk of infection and willingness to be vaccinated, as the vaccination programme proceeds.

Source: Skivington et al. (2021; p3)

Like the second version of the MRC guidance, the third version divides complex intervention research into four phases: development or identification of the intervention, feasibility, evaluation, and implementation (Figure 4.4). However, unlike its predecessor, the third version emphasises that a research programme might begin at any phase, depending on the key uncertainties about the intervention in question (Skivington et al., 2021). It further provides a common set of core elements for each phase – considering context, developing, and refining programme theory, engaging stakeholders, identifying key uncertainties, refining the intervention, and economic considerations (Figure 3.4). However, this work was not available when the intervention delivered in this thesis was developed.

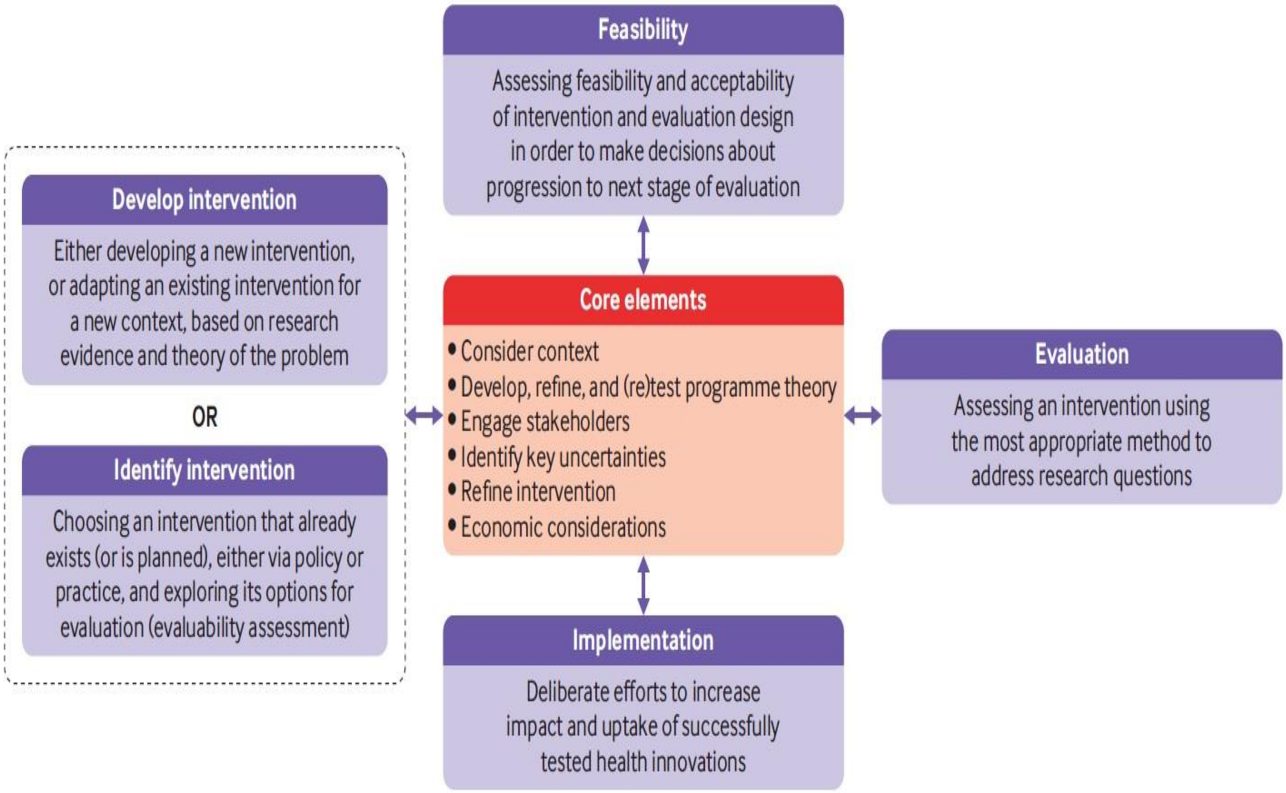


Figure 4.4: Framework for developing and evaluating complex interventions, reproduced from Skivington et al. 2021, page 4

4.14 Comparing the MRC framework with other intervention development frameworks

Prior to the publication of the MRC Framework in 2000, there were other intervention frameworks including Intervention Mapping (IM) (Bartholomew-Eldredge et al., 1998), the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework (Glasgow et al., 1999), and the PRECEDE-PROCEED model (Green and Kreuter, 1999). Those frameworks required technical skills and resources to apply, were focused on social-psychology and individual behaviour change, or provided little detail on intervention development (Wight et al., 2016).

4.15 Rationale for choosing the MRC Framework for this PhD project

This thesis follows the second version of the MRC Framework for Developing and Evaluating Complex Healthcare Interventions which was the most cited intervention development framework across different disciplines (Fletcher et al., 2016, Owens et al., 2011, Bleijenberg et al., 2018, Bobrow et al., 2018, Lakshman et al., 2014) when the intervention employed in this thesis was developed. The rationale for choosing the MRC framework is that this thesis employs a complex intervention study which has several interacting components (e.g., staff education, toileting exercises, diet and fluid intake, and review of polypharmacy) (Chapter 7), with the flexibility of how care staff assess and tailor the various components of the intervention to individual residents.

The MRC Framework serves as a conceptual framework which maps how all the literature work together in this thesis. A systematic review assessing the most comprehensive approach to developing complex interventions for nursing research and practice identified that the only guideline reported to have been used in the development of interventions is the MRC framework, with 9 of 14 papers that described the development of an intervention reporting the use of the guideline (Corry et al., 2013). A scoping review of 27 included studies on the availability of evidence relating to strategies and methods to optimise development of complex interventions found that 17 of their included studies referred to the MRC framework (Levati et al., 2016). Most importantly, all the studies that referred to the MRC framework used either the first version of the framework (Campbell et al., 2000), or the second version of the framework (Craig et al., 2008). Although that does not necessarily mean that the use of the framework guarantees successful development and implementation of an intervention, it does draw attention to methods which are known to work (Craig et al., 2013).

The MRC Framework is widely accepted by the research community, as evident by the revised doctoral summer school curriculum of the European Academy of Nursing Science (EANS), a scientific community that provides inspiration, collaboration and academic leadership in nursing (Möhler et al., 2012). Its popularity and strength seem to stem from its inherent flexibility and non-linear approach (Chalmers et al., 2014, Fletcher et al., 2016, Owens et al., 2011), which may be usefully applied to the iterative intervention development processes that were involved in this PhD project.

4.16 Application of the MRC framework to this PhD project

This PhD research project is built on findings from a previous realist synthesis (FINCH review) (Goodman et al., 2017), which investigated managing faecal incontinence in older people with advanced dementia in care homes. The review was funded by the National Institute for Health Research Health Technology Assessment programme, and it was conducted by researchers, two of whom are supervisors to the PhD candidate. The realist synthesis drew together evidence from different strands of research to inform interventions that address the realities of working in and across complex overlapping systems of care. For example, it sought evidence on the physiology and management of FI and urinary incontinence (UI) in ageing populations and those living with dementia in care homes, and the relative availability, acceptability and efficacy of different types of incontinence products (Goodman et al., 2017). It also included experiential evidence on living with dementia and incontinence from the perspectives of people with dementia and their paid and unpaid carers.

A further description of this realist synthesis (FINCH Review) is presented in Chapter 5 of this thesis. The findings of the FINCH review were crucial to the development of the intervention that is employed in this PhD project, especially in terms of theory development for incontinence care in care homes. However, a clear distinction is made between work already completed before this PhD research project, and those elements that form part of this PhD (Figure 4.1).

4.16.1 Development Phase

The developmental phase of this thesis focused on the rationale for intervention development. In accordance with the second version of the MRC Framework, the starting point for the PhD candidate was to explore existing knowledge on faecal incontinence among older people living in care homes and this led to unravelling of the gaps that exist in the literature that necessitate intervention. To achieve this, the PhD candidate undertook two literature reviews: (i) The prevalence, incidence, and correlates of faecal incontinence among older people living in care homes (Musa et al., 2019) (PhD Paper-1, Chapter 2) and (ii) Interventions for treating or managing faecal incontinence in older people living in care homes (Musa et al. [submitted, Chapter 3]). The two reviews helped to fill the gaps in the literature, thus enabling definition of the research questions and the methodologies to address those questions. Details of the two systematic literature reviews are contained in Chapters 2 and 3.

The MRC framework also encourages researchers to base interventions on theories by either formulating or relying on already existing theories (Craig et al., 2008). To develop a theory-driven intervention, this thesis builds on the programme theories proposed by the FINCH Study (Goodman et al., 2017). The FINCH programme theories provide comprehensive insight on factors that serve as facilitators (and barriers) in carrying out bowel care interventions in older residents who are incontinent and living with dementia in care homes. The programme theories provide a theoretical understanding of a likely change process in terms of contexts and mechanisms of outcomes (reduction in frequency of FI) in the care home population.

Evolving evidence suggests that adherence to healthcare interventions derives from stakeholders' participation in identifying relevant problems and helping to formulate interventional strategies that are feasible and acceptable to the service users (Fletcher et al., 2016, O'Cathain et al., 2019). Therefore, this PhD research study employed a stakeholders' consultation during the intervention development phase to help reach a consensus intervention that would be feasible and acceptable to the people experiencing FI as well as those providing continence care. Stakeholders' involvement in research had led to improvements for example, regarding recruitment, retention (less loss to follow up), data quality, data interpretation and dissemination of findings (ICPHR 2013).

Stakeholders' engagement in this thesis conforms with the third version of the MRC guidance, which provides a set of core elements including stakeholders' engagement (Skivington et al. 2021). The stakeholders in this project included care home residents experiencing FI (and their relatives), care home staff and commissioners and/or managers working in a care home. The rationale for choosing these groups of stakeholders is detailed below (Table 4.3). It involved focus group discussions and semi-structured interviews, as detailed in Chapter 6.

Following the stakeholders’ consultation, evidence was collated from the two reviews conducted by the PhD candidate (Chapters 2 and 3) and the contribution made by the stakeholders (Chapter 7) to model a bowel care intervention using intervention mapping approaches (Bartholomew-Eldredge et al., 2016, Hurley et al., 2016). Details of the intervention mapping is presented in Chapter 7 of this thesis.

Table 4.3: Rationale for selection of stakeholder groups

Targeted stakeholder group	Rationale
Recipients of care Care home residents (identified through the care staff) and family carers with experience of caring for a relative living with FI in a care home.	Residents and their family members were chosen to give the closest possible approximation of residents' own opinions of continence care.
Care home staff Nurses, care assistants, dieticians, physiotherapists, and pharmacists.	Care home staff understand actual practice and therefore provide an invaluable insight into how continence care is managed.
Providers of care Commissioner/Care home manager/Unit manager	Care home manager (and Unit Managers) know and understand organisational processes, protocols and 'industry' best practice and are aware of how well all rules and guidelines are applied within the care homes in which they work. Additionally, they are aware of factors that inhibit or facilitate the implementation of the rules and guidelines.

4.16.2 The feasibility Phase

The second phase of the MRC framework concentrates on feasibility/pilot study. In this thesis, a model multicomponent intervention was tested in multiple case studies in a care home. With this focus, a realist enquiry of what works and for whom (Pawson et al., 2005), the model intervention was tested for its feasibility. The feasibility study focused on key sets of core elements that were considered contextual factors (e.g., individual care home residents characteristics and the care home's environment), and identification of uncertainties in terms of components of the intervention (Skivington et al. 2021).

4.17 The Evaluation Phase

The evaluation phase of the MRC Framework aims to establish links between the intervention and its effect (Craig et al. 2008). During this phase, the choice of design strategy is one crucial factor, which determines the ability of the evaluation to show the effects of the intervention as good an approximation of the 'real' effect as possible. One typical way of controlling potential confounders is by means of randomisation, which as mentioned earlier, cannot always be possible (e.g., it may be unethical to randomise research participants). In such situation, researchers are required to employ other means to establish causality (Richards and Hallberg, 2015).

This PhD research project did not cover the evaluation phase of the MRC Framework due to time constraint.

4.18 The Implementation Phase

Implementation is the use of strategies to adopt and integrate clinical research findings and other evidence-based practices into routine practice and hence improve the quality and effectiveness of health care within specific settings (Damschroder et al., 2009, Implementation Science, 2022, McCormack et al., 2010, Nilsen, 2015). This encompasses not using practices demonstrated to be of low or no clinical benefit to patients, healthcare professionals, and/or the healthcare organisation.

Because of time constraints on completion of this PhD project, the implementation stage of the MRC framework, particularly monitoring, surveillance and long-term follow-up of the intervention is beyond the scope of the current research study. However, dissemination of results from the intervention will be through peer reviewed publications and conference presentations where possible. Dissemination is the targeted distribution of information and intervention materials to a specific public health or clinical practice audience (Glasgow et al., 2012). The intent is to spread research knowledge and the associated evidence-based interventions.

Summary of how the second version of the MRC Framework is applied to this thesis is presented in Figure 4.5 below. How stages of the MRC framework contributed to the intervention development in this thesis is summarised in Table 4.4 below.

Prevalence Review on FI.
Cochrane Intervention Review.
FINCH Programme theories:

- Stakeholders' consultation
- Modelling of a bowel care intervention

Use of multiple case studies to test feasibility of a multicomponent intervention

- ➢ Is the intervention feasible?
- ➢ Is the intervention attractive/acceptable to the participants/staff?
- ➢ Does the

Presentation of results

- ✓ Thesis
- ✓ Publications in peer-reviewed journals
- ✓ Conference attendance

Not covered in this thesis due to time constraint to complete PhD studies.

Figure 4.5: Summary of how the revised MRC Framework is applied to this PhD Project

Table 4.4: Contribution of the phases of the MRC framework to the development of the intervention

	Development Phase			**Feasibility Phase**
MRC stages	**Identifying the evidence base**	**Identifying and/or developing the theory**	**Modelling process and outcome**	**Testing procedures**
Aims	To identify the magnitude of the FI among older people in care homes, as well as the evidence-base for bowel care interventions.	To identify appropriate theory as the basis for developing bowel care intervention.	To consult with stakeholders on what bowel care intervention best work to manage or treat FI in care homes.	• To test the procedures of bowel care intervention for older people living in care homes. • To test feasibility of FI intervention in the care home.
Inquiry	• How widespread is FI among older people living in care homes and what are the causes of FI in this sub-group of the population? • What is the best available intervention for managing and/or treating FI in older people living in care homes?	Is there any theory or programme theory that inform how bowel care intervention may be developed and delivered successfully?	Which mechanisms are relevant, giving certain contextual factors, to lead to reduction of FI and acceptability of the intervention in the long term?	• How feasible is bowel care intervention that aims to reduce FI among older people living in care home? • How acceptable is the intervention by residents and providers of continence care?
Methods	Systematic reviews	Programme theories proposed by the FINCH Review is tested in a stakeholders' consultation.	Results from PhD Papers 1 & 2, the FINCH programme theories, Stakeholders' consultation, and guidance from supervisory team.	Pretest-posttest design & Multiple case studies
Output	PhD Papers 1 and 2	Chapters 5 & 6	Chapter 7	Chapter 8

4.19 Study design and methods

This PhD project employed emergent mixed-methods design, informed by realist programme theories. A number of research approaches have been used in this thesis to gather evidence to develop an intervention and test it in a feasibility study (Figure 4.5). For example, to gather the evidence-base for intervention development, a systematic review of FI prevalence using JBI checklist for critical appraisals and the Cochrane Review of interventions for FI were used (Chapters 2 and 3 respectively). The systematic reviews followed programme theory refinement using realist evaluation approaches (Chapter 6). Using the six steps in intervention development helped to combine the evidence and theory to develop a bowel care intervention in this thesis (Chapter 7). The intervention was then tested using two approaches – pre-test and post-test, as well as multiple case studies (Chapter 8).

4.19.1 Rationale for a mixed methods approach

Mixed-methods research is the combination of both qualitative and quantitative strands in terms of collecting, analysing and interpreting data in a single or series of studies that investigate the same phenomenon (Creswell and Clark, 2007). The rationale for using a mixed-methods approach is that it provides better understanding of research questions that deal with real-life contextual understandings and/or cultural influences than either of the mono-method research (qualitative or quantitative) approaches alone (Creswell and Clark, 2011). Mixed-methods designs can broadly be categorised as fixed mixed-methods designs, and emergent mixed-methods designs. In the former, mixing of qualitative and quantitative data are planned at the beginning of the research process; whereas in the latter approach, the need to combine qualitative and quantitative data arises as issues develop while conducting the research (Creswell and Clark, 2011). The study design followed in this research study is an emergent mixed-methods design.

In this PhD project, both qualitative and quantitative strands of data are given equal priority in addressing the research problem, hence the approach will simply be described as ‘equivalent’ in terms of data contribution to the overall objective of the research study. The timing, also referred to as pacing and implementation (Creswell and Clark, 2007), is 'concurrent', which means both qualitative and quantitative strands were conducted during the same phase of the study (where practicable) to aid completeness and triangulation (Bryman, 2006). The point of interface (also known as the stage of integration) is a point in mixed-methods research where the qualitative and quantitative strands are mixed (Morse, 2009). In this PhD project, mixing of data occurred during data analysis. First, individual strands of the data were analysed separately. Then using an interactive strategy of merging, the two sets of results were combined (where possible) by relating them to each other in a matrix that facilitates comparison and interpretations (Creswell and Clark, 2011).

To further facilitate success of a bowel care intervention, a theory-driven approach, grounded in realism (Pawson and Tilly, 1997) was employed to determine what interventions work or not, what mechanisms drive certain interventions to success or failure, and within what context a particular intervention flourishes or perishes. Details of the realist approaches are explored in other sections below.

4.19.2 Realist evaluation

There is an established body of knowledge about what supports implementation of evidence in practice. For example, the Promoting Action on Research Implementation in Health Services (PARiHS) (Rycroft-Malone, 2004), the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009), and the Knowledge to Action Framework (KTA) (Graham et al., 2006). Crucially, implementation planning is about identifying determinants of innovative programmes including barriers and facilitators (Field et al., 2014). The realist evaluation approaches (Pawson and Tilley, 1997) can complement and inform implementation planning because realist evaluation is interested in establishing causal mechanisms that can go beyond identification of barriers and facilitators. It also extends the work of the FINCH review (Goodman et al., 2017), which is the starting point of this PhD research project.

Box 1 below provides the glossary of realist terms and how they have been applied throughout in this thesis.

Box 1: Definitions of realist terms and how they have been applied throughout the thesis

Context (C): the 'backdrop' conditions (which may change over time) (Jagosh et al., 2014); for example, provision of training in FI continence care, residents' level of nutrition and hydration. Context can be broadly understood as any condition that triggers and/or modifies the behaviour of a mechanism (Astbury, 2013).
Mechanism (M): the generative forces, powers, processes, or interactions that lead to (or inhibit) change, which can be the choices, reasoning, and decisions that people make as a result of the resources a programme provides (Punton et al., 2020). Mechanisms are activated or inhibited by circumstances or contexts that then have an effect (Maidment et al., 2020). In this research study, mechanisms include the reasoning (e.g., cognitive, or emotional) of the various 'actors' (e.g., residents, relatives, and care home staff) and resources (e.g., the expertise of clinicians, bowel care information).
Outcomes (O): any changes brought about by the programme (Pawson and Tilley, 1997), which may be planned or unplanned, visible or not (Maidment et al., 2020). In this research study, outcomes include reduction in episodes of FI (or no changes in FI episodes), improvement in resident distress (or no changes in residents' distress level), and increase (or decrease) in staff confidence.
Programme theory: explains (some of) 'how and why, in the "real world", a specific programme "works", for whom, to what extent and in which contexts' (Astbury and Leeuw, 2010, Wong et al., 2016). In this research study, it connotes ideas about what needs to be changed or improved in how FI is reduced and managed in older people living in care homes; what needs to be in place to achieve an improvement and how this is believed to work.
Demi-regularities – a prominent, recurrent patterns of contexts and outcomes in the data (Wong et al., 2014, Wong et al., 2016).
Context-Mechanism-Outcome (CMO) – The association of causal components that explain what works in an intervention/programme for who, why and in which circumstances (Jagosh, 2020, Maidment et al., 2020, Pawson and Tilley, 1997, Westhorp, 2014).

The Realist Evaluation (RE) approach seeks to identify not just whether a programme has been successful, but how and why the programme outcomes are achieved (Greenhalgh and Manzano, 2021, Pawson, 2013, Westhorp, 2014). Realist evaluation asks what works for whom in what circumstances (Pawson and Tilley, 1997). It enables explanations about how context dependent interventions and their outcomes are likely to work (or not) (Fletcher et al., 2016, Gilmore et al., 2019). Realist evaluation is an iterative inquiry that starts with an initial programme theory and ends with a refined programme theory (Greenhalgh et al., 2018, Pawson, 2013).

Realist evaluation focuses on middle-range theories (as opposed to grand or meta theories) to provide explanation of how and why different actors respond the ways they do. Middle-range theory, according to Robert K. Merton (1968), consists of a set of assumptions from which a specific hypothesis is logically derived and subsequently confirmed by empirical investigation. Merton (1968; page 39) defines middle-range theory as a theory "*that lies between the minor [theories] but necessary working hypotheses that evolve in abundance during day-to-day research and the all-inclusive systematic efforts to develop a unified* *theory that will explain all the observed uniformities of social behaviour, social organisation and social change*". The development of middle-range theories that reveal the contexts and mechanisms under which the outcomes of the intervention can be generated can provide the basis for understanding a family of related interventions and contexts (Astbury, 2013, Tan and Harvey, 2016, Westhorp, 2014).

Realist evaluation addresses the limitations of reporting on social programmes primarily in terms of effects, with little attention paid to how those effects are produced (Salter and Kothari, 2014, Tan and Harvey, 2016, Astbury and Leeuw, 2010). An enduring feature of complex, socially driven interventions is the variability in how the interventions are implemented. Realist evaluation encourages alternative theorising about how an intervention works (Chen, 2012). In realist evaluation the research process begins with theorising (e.g., about what? And how?), testing those theories; the theories are then refined and tested again (Mukumbang et al., 2016). It is this iterative process that supports an understanding of the real world (Manzano, 2016).

Realist evaluation, as with all research methodologies, is subject to limitations and specifically research bias and influence (Jack and Linsley, 2021). For example, mechanisms in RE are theories of human actions and reactions, so it is possible that the choice of mechanism to be included in a context-mechanism-outcome configuration is heavily influenced by the researcher and thus may not be the most applicable in the situation under investigation (Kazi, 2000). This can be a particular risk when the researcher is identifying mechanisms influenced by their own clinical experiences and presuppositions (Jack and Linsley, 2021).

Realist evaluation is not a method or a technical procedure; rather it is a logic of inquiry that attempts to answer the question, (Jackson and Kolla, 2012, Jagosh et al., 2012, Pawson and Tilley, 1997, Westhrop, 2018). This is accomplished through the identification and examination of underlying generative mechanisms (M) associated with the intervention or programme, the conditions or contexts (C) under which the mechanisms operate, and the pattern of outcomes (O) produced (Greenhalgh et al., 2009, Hewitt et al., 2014, Pawson and

Tilley, 2004, Salter and Kothari, 2014). This, Pawson and Tilley suggest, may be expressed as linked C-M-O configurations (or C +M=O) (Pawson and Tilley, 1997).

It is a standard realist proposition that the relationship between generative mechanisms (Blom and Morén, 2011) and their effects is not fixed, but is contingent on contextual conditioning (Pawson and Tilley, 1997). All programmes have a common underlying mechanism, namely, to insert resources in the expectation (i.e., theory) of changing the choices open to subjects (Pawson, 2010). Realist evaluation argues that interventions are driven by 'mechanisms' that are not often directly observable but have an impact of the way the people involved reason about how to use the resource (Dalkin et al., 2015). For example, in a hypothetical intervention to improve faecal incontinence in the care home setting, the support care staff receive through clinical supervision and training (i.e., resource) may help individual staff to build up confidence (i.e., reasoning) in how to perform bowel care. In this example, the rarely observable mechanisms are the combination of the resource and reasoning of the care staff (e.g., the staff feel confident because they get support from a particular clinician and they get more information by attending training, and that makes the staff more analytical and proactive). A further analysis of what 'mechanisms' are in realist evaluation is discussed below.

Realists recognise that no intervention will ever work the same way everywhere and/or for everyone (Gilmore, 2019). In some contexts, some programme offerings will work, and in others, they will not (Pawson, 2013, Paz-Ybarnegaray and Douthwaite, 2016). This is also true for the research study undertaken in this thesis – findings are not to be applied in other settings without taking context into consideration.

4.19.3 Context-mechanism-outcome

The challenges of realist research are identifying precisely what are the mechanisms (Astbury, 2013) and differentiating elements of context from mechanisms (Marchal et al., 2012). Some authors have reported that the definitions of context and mechanisms are too broad, which makes it difficult to distinguish context from mechanism in the data (Astbury and Leeuw, 2010, Bergeron and Gaboury, 2020, Marchal et al., 2012). This difficulty may be explained by the fact that there are multiple levels for elements of contexts and mechanisms (Dalkin et al., 2015, Pawson, 2015). Therefore, a context in one circumstance might be a mechanism or even an outcome into another configuration (Bergeron and Gaboury, 2020, Westhrop, 2018). For example, in the hypothetical bowel care intervention mentioned above, the support care staff receive through clinical supervision and training, which was the mechanism, could in fact be a context in a care home where such resources are the starting point of care.

4.19.4 What are 'contexts' in realism?

Realism provides a specific way of thinking about 'context'. Whether mechanisms 'fire' (operate at a particular moment) depends on the context (Westhorp, 2014). Contexts are often the 'backdrop' of interventions (Jagosh et al., 2014). Context refers to the setting for human actions and includes both fixed characteristics, such as geography and organisation, and variable human characteristics, such as culture and leadership (Ellaway et al., 2020). The context within which the organisation implementing a programme can influence the way in which, or the extent to which, a programme is implemented, who it targets, who it reaches and so on. However, it can also influence the ways in which intended beneficiaries respond (Westhorp, 2014). For example, responses to an intervention may differ depending on whether the programme is delivered by healthcare staff, or by researchers. This is particularly relevant to care homes where different participants' experiences and the care home environments can lead to different responses and interactions.

There are no accepted definitions of what context is in general terms (Coldwell, 2018, Ebenso et al., 2019, Shaw et al., 2018b). A recent review of realist evaluations and syntheses provides two key narratives of how context is conceptualised: (1) Context as observable features (space, place, people, things) that triggered or blocked the intervention; assuming that context operates at one moment in time and sets in motion a chain reaction of events; and (2) Context as the relational and dynamic features that shaped the mechanisms through which the intervention works; assuming that context operates in a dynamic, emergent way over time at multiple different levels of the social system (Greenhalgh and Manzano, 2021). When applied to earlier work and this study, the need for a geriatrician to carry out FI assessment may not be so relevant in situations where there are nurses with advanced practitioner roles involved in continence assessments.

4.19.5 What are ‘mechanisms’ in realism?

Realism offers a particular understanding of how causation works. In realist thinking, the underlying causal process is known as a ‘mechanism’ (Westhorp, 2014). There are two other important things to understand about the idea of mechanisms. The first is that they exist as part of a whole system; the second is that mechanisms exist whether or not they are operating at a particular moment (Westhorp, 2014).

Pawson and Tilley (1997) were the first to clarify the implications of the realist understanding of ‘mechanisms’ for programme and policy evaluation. They asked what the ‘causal powers’ of programmes might be. They argued that programmes provide something – a resource, an opportunity or a constraint of some kind – that is intended to influence the target person’s decision-making (Pawson and Tilley, 1997, Westhorp, 2014). Mechanisms or circumstances are not observed directly but enable researchers to ask, “what is it about programmes that make them work?” (Jagosh et al., 2012, Jagosh et al., 2014). The mechanisms of change are always contingent on context, because what works in one place and time may be ineffective elsewhere (Moore and Evans, 2017). Thus, mechanisms are a key construct in the ability for realist inquiry to generalise beyond the specific (Ellaway et al., 2020).

There are three key characteristics of mechanisms: they are hidden, context-dependent and they generate outcomes (e.g., in one context, mechanisms may lead to ‘x’ outcomes; and in another context, the same mechanisms may lead to ‘y’ outcomes”) (Astbury and Leeuw, 2010, Dalkin et al., 2015, Handley et al., 2019). However, the PhD candidate is aware of the ongoing debate in the literature concerning what constitutes mechanisms and how they are used in realist research. While Pawson and Tilley (Pawson and Tilley, 1997) describe mechanism as resource and reasoning that is ‘fired’ or ‘triggered’ by a contextual factor to create an outcome (much like off/on response), Dalkin and colleagues suggest disaggregating resource and reasoning as mechanisms, and argue that mechanisms operate on a continuum (using a metaphor of ‘dimmer light switch’) (Dalkin et al., 2015). In this thesis both resource and reasoning are treated as ‘mechanisms,’ in accordance with Pawson and Tilley (1997), as shown in Figure 4.6. However, for clarity, the concepts of ‘resource’ and ‘reasoning’ are described wherever necessary.

From the PhD candidate's own experience of working in care homes, interventions in this setting are influenced by multiple factors (e.g., staffing levels, changes in care home administration, budgetary constraints, lack of staff training, etc.). This part of the thesis looked at what was specific to the delivery of care for older people with dementia and FI living in care homes as found by FINCH review (Goodman et al., 2017), but also argued that there are other significant factors not previously discussed that shape how well (or not) FI is managed.

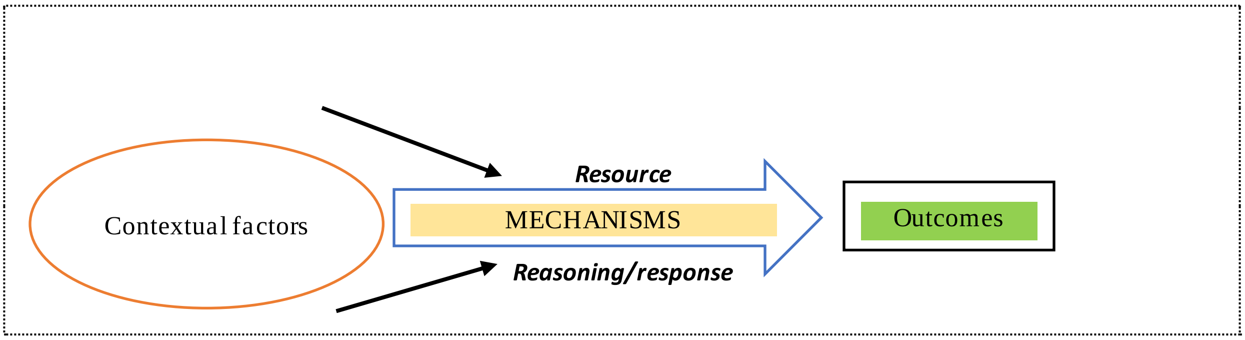


Figure 4.6: Summary of how mechanism is conceptualised in this realist evaluation

4.19.6 What are outcomes in realism?

Realists use the term 'outcome' to include short, medium and long term changes, intended and unintended, resulting from an intervention (Westhorp, 2014). Therefore, outcomes of interventions are dynamic, and may be planned or unplanned, distal or proximal, intermediate or final (Rycroft-Malone et al., 2016). Realists posit that any outcome that is observed will be a result of interactions within and across systems – not simply an outcome of the programme (Westhorp, 2014). How a context shapes how a mechanism is triggered to produce or contribute to a particular outcome is called a context–mechanism–outcome (CMO) configuration (Pawson, 2006b). It is by identifying the relationships between the study context(s) and the mechanism(s) that produces the outcome(s) that realist inquiry seeks to explain how and why interventions work or fail to work (Ellaway et al., 2020). For example, in the FINCH review (Goodman et al., 2017), the authors proposed that a reduction in FI episodes and the use of toilet for defaecation (O) may be achieved when clinician-led bowel and continence assessment exists (C). However, to achieve this will require additional staff to engage with the clinician and spend time on FI-related care (M).

4.19.7 Realist evaluation programme theories

Pawson has stated that programmes are 'theories incarnate' and that every programme has a theoretical underpinning, whether it is made explicit or not (Pawson and Tilley, 2004). A programme theory is the overarching theory or model of how a programme is expected to work (Maden et al., 2017). It can include positive impacts (which are beneficial) and negative impacts (which are detrimental). It specifies the components of a programme (or intervention) intended to mitigate or resolve the problem and the expected outcomes. It is explicit about the rationale and assumptions about mechanisms that link a programme's processes and inputs to outcomes – and specifies the conditions (or context) necessary for change (Jackson and Kolla, 2012, Pawson et al., 2005). The 'theory' in a programme theory can be an articulation of practice wisdom or of tacit assumptions – that is, it can be more than a formal, research-based theory (Maden et al., 2017).

A programme theory brings together existing evidence clarifying where there is agreement and disagreement about how the programme is understood to work, and where there are gaps in the evidence (Maden et al., 2017, Rogers, 2008). It is often developed during the planning stage of a new intervention and can also be developed during implementation and even after a programme has finished (Browne et al., 2021, Flynn et al., 2019, Wilkinson et al., 2021). When an evaluation is being planned, it is useful to review the programme theory and revise or elaborate it if necessary (Wong et al., 2016). A programme theory can be developed by programme staff, by an external evaluator, by programme designers, or collaboratively with the stakeholders who are expected to benefit from and/or deliver a programme (Jackson and Kolla, 2012, Jagosh et al., 2014, Pawson, 2013).

In this realist evaluation, the programme theories to be tested are the FINCH programme theories (Goodman et al., 2017). As summarised in the preceding chapter, the FINCH review (Goodman et al., 2017) proposed six broad theory areas that could explain how to improve continence care for people living with dementia and FI in care homes. These theory areas are: (1) clinician-led support, assessment, and review; (2) ongoing teaching, review, and feedback to care staff on how to reduce and manage FI; (3) addressing the causes and prevention of constipation; (4) interventions that reflect the degree of cognitive and physical capacity of the resident; (5) common understanding of the potential for recovery and reduction of FI; and (6) integrating care for people living with dementia and FI into everyday work patterns of the care home and staff (Goodman et al. 2017). However, the authors acknowledged in their review that few included studies sufficiently addressed the way in which dementia affects the uptake of different interventions or the dementia-specific continence skills that staff require (Goodman et al., 2017). The stakeholders' consultation, therefore, extended the theory development work of FINCH review before embarking upon intervention development for care home residents living with dementia.

4.20 Chapter summary

The overall aim of this PhD research study was to develop an intervention that takes account of the complexities of the care home characteristics (both individual residents and institutional) and the multiple underlying causes of FI in older people residing in care homes. Thus, the methodological choices were made to avoid research waste and to develop an intervention that is person-centred. The second version of the MRC framework was utilised to guide each step of the intervention development process, including appropriate methods of implementation. The use of realist evaluation approaches (Chapter 6) helped to contextualise the intervention. And finally, the use of TIDieR, a reporting guideline for interventions (Hoffmann et al., 2014) was used to guide the reporting of the feasibility study (Chapter 8).

Chapter 5: Critical analysis of the FINCH programme theories

This chapter sets out the theoretical basis for the thesis. It outlines ongoing research challenges in terms of interventions aimed at managing faecal incontinence among older people living in care homes, especially for those with underlying comorbidity such as dementia. The chapter then introduces findings of a realist review on the management of '**f**aecal **in**continence in people with advanced dementia living in **c**are **h**omes' (FINCH) (Goodman et al., 2017). It concludes by outlining key limitations of the FINCH review and recommends further testing and refinement of the programme theories through stakeholders' engagement.

5.1 Background

The care home sector is diverse, varying in size, ownership, funding sources, focus, education of the workforce and organisational culture (Laing and Buisson, 2014). This variability in provision has implications for the way in which interventions to support older people such as continence care are understood and implemented (Peryer et al., 2022). For example, the presence or absence of on-site nurses, topic expertise in the workforce, organisational structure, funding and staffing may impact on how junior care staff prioritise residents' specific care needs (Goodman et al., 2017).

The evidence about the management and prevention of faecal incontinence (FI) in care homes is sparse. Research on continence care in care homes tends to focus on urinary incontinence (UI) (Flanagan et al., 2012, Flanagan et al., 2014, Rodriguez et al., 2007, Roe et al., 2011, Roe et al., 2013). Essentially, there is a body of continence research in US care homes (some of which is focused on FI) (Leung and Schnelle, 2008, Levy-Storms et al., 2007, Nelson et al., 1998, Ouslander et al., 1996b, Rahman and Applebaum, 2009, Schnelle et al., 2003, Schnelle et al., 2011, Schnelle et al., 2010), but among these studies, there is little consideration of the impact of comorbidity such as the impact of dementia on continence, or how contextual factors may impact on continence care within the care home setting. Although there is good evidence about risk factors (including impact of comorbidities) for FI in older people living in care homes (Bliss et al., 2013, Musa et al., 2019, Saga et al., 2013), there are few intervention studies on the management of FI among this subgroup of the population (Bates-Jensen et al., 2003, Blekken et al., 2015c, Bliss et al., 2001, Chassagne et al., 2000, Schnelle et al., 2002, Schnelle et al., 2011, Tobin and Brocklehurst, 1986) and little conclusive evidence of what is effective management of FI in people resident in care homes (Flanagan et al., 2012, Flanagan et al., 2014, Goodman et al., 2017).

A recent Cochrane systematic review of intervention for FI among older people living in care homes led by the PhD candidate found that existing interventional studies either failed to show improvement in reducing FI or showed very limited improvement in FI episodes (Musa et al. [submitted]). There remains limited evidence to support any treatment beyond three to six months after research activities (Guinane and Crone, 2018). A noticeable trend among the research studies that have attempted to address management and/or treatment of FI in this sub-group of the population is that either the practice has been invasive (e.g. use of laxatives such enemas) (Chassagne et al., 2000), or the intervention did not account for individual resident and care home characteristics (e.g. either treated every care home resident the same, or did not give account of the effect of dementia on continence care in their interventions) (Blekken et al., 2015c, Bliss et al., 2001, Khaja et al., 2005, Schnelle et al., 2010, Tobin and Brocklehurst, 1986). Meanwhile, evidence suggests that the effectiveness of programmes to address a known problem such as FI in care homes is contingent not only on specific bowel-focused interventions, but also on contextually situated decision-making (Peryer et al., 2022, Rycroft-Malone, 2008).

5.2 Literature on the management of faecal incontinence in care homes

More than fifty percent of care home residents are incontinent of faeces, urine, or both (Ihnat et al., 2016, National Institute for Health and Care Excellence (NICE), 2014, Ouslander et al., 1995). Most incontinent residents have some combination of cognitive and physical impairments that limit their ability to toilet and/or change their soiled or wet garments, relying on assistance from nursing staff (especially from healthcare assistants) (Akpan et al., 2007, Al-Samarrai et al., 2007, International Continence Society (ICS), 2015). Practice guidelines specify that a resident’s soiled garments should be changed, and skin cleansed in a timely fashion (American Medical Directors Association (AMDA), 2011, National Institute for Health and Care Excellence (NICE), 2007b, National Institute for Health and Care

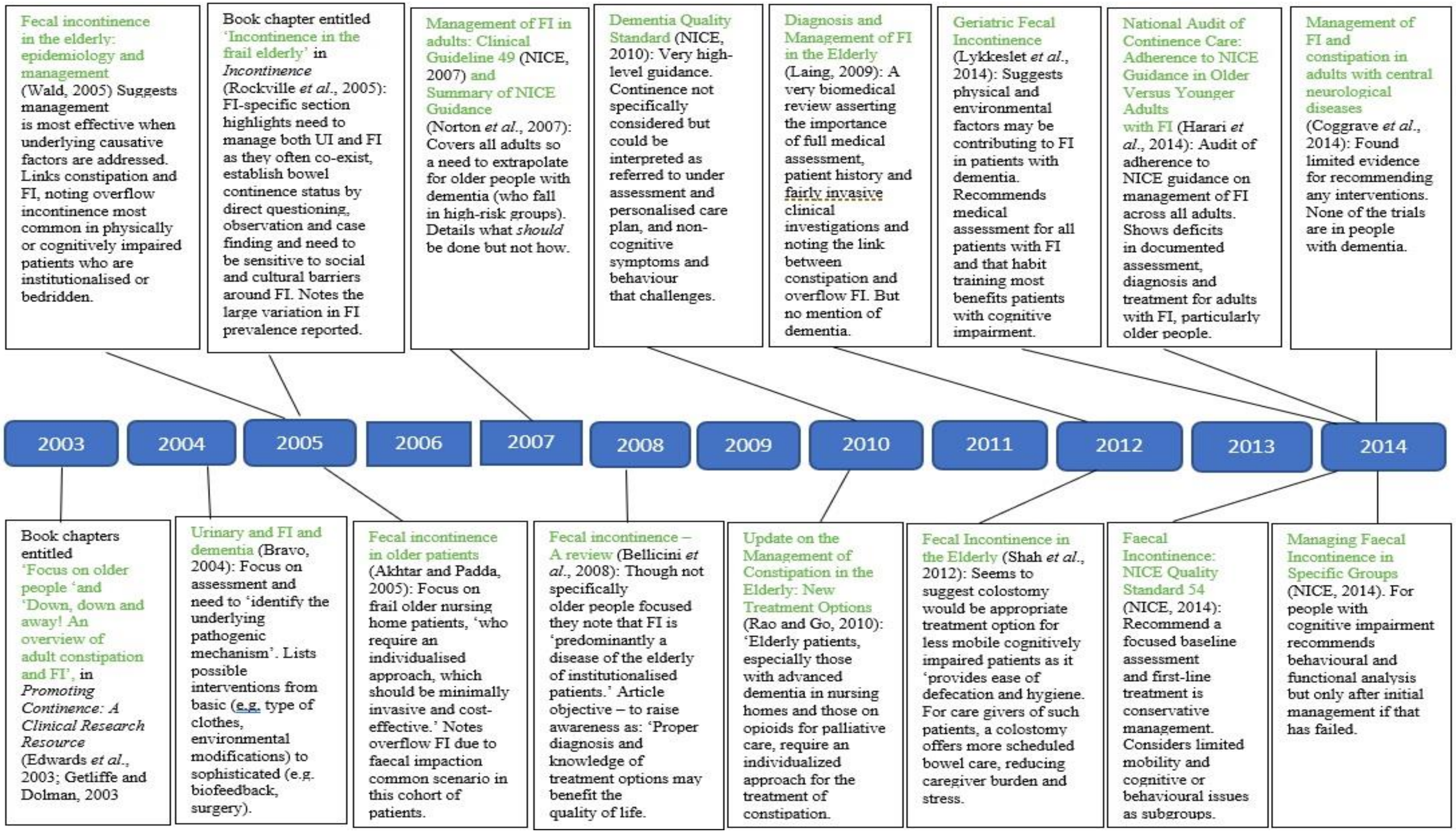
Excellence (NICE), 2014, Savarino et al., 2022). However, little data exists describing the amount of time required to implement incontinence care activities, and there is even less data about how better skin cleansing might improve outcomes (Al-Samarrai et al., 2007).

The literature on management of incontinence among older people has mostly concentrated on the use of absorbent pads (incontinent pads) (Al-Samarrai et al., 2007). A cumulative body of work in continence research in care homes (mostly on urinary incontinence) in the United States by Ouslander and colleagues and Schnelle and colleagues demonstrates how interventions in continence care have been progressively refined over time, with an increasing emphasis on the involvement of care home staff in training and structured programmes of prompted voiding (Leung and Schnelle, 2008, Levy-Storms et al., 2007, Ouslander et al., 2005, Ouslander et al., 1995, Schnelle et al., 2002, Schnelle et al., 2003, Schnelle et al., 2011, Schnelle et al., 2013, Schnelle et al., 2009). There is, however, a lack of evidence or guidance about how to implement these approaches in settings with limited access to doctors or how a person's dementia will have an impact on implementation (Buswell et al., 2017). Nevertheless, among these sources of evidence is a strong theme on the belief that direct clinical assessment of a resident is essential, but there is little guidance on how this could be achieved.

Figure 5.1 demonstrates how thinking about management of FI in older people living in care homes is discussed in guidance and review articles for healthcare professionals. A strong theme that emerges from those evidence sources (Figure 5.1) is the belief that direct clinical assessment of an incontinent resident is essential, but there is limited acknowledgement or guidance about how to implement this essentially biomedical guidance (e.g., careful examination of the anorectal region is recommended by NICE) in settings with limited access to clinicians. There is also a lack of discussion about how to implement assessment or treatment options for people living with dementia. The lack of continence studies addressing dementia, and the inconsistency in how dementia is assessed and recorded for care home residents meant that the FINCH review (Goodman et al., 2017) considered potentially transferrable learning from research studies on person-centred care and non-pharmacological approaches to the reduction and management of behavioural and psychological symptoms of dementia in care homes (Ballard et al., 2001, Fossey et al., 2014).

The authors hypothesised that it was unhelpful to create distinction between what is continence care and what is personal or intimate care (Buswell et al., 2017, Goodman et al., 2017).

Notwithstanding, thinking about how older people with FI living in care homes has changed since 2014 (Figure 5.1). For example, there have been considerations for offering training to care staff on FI with structured guidelines and facilitation. A pilot study by Blekken and colleagues (2015) concluded that FI can be prevented, cured, or ameliorated by offering care staff knowledge of best practice. The same study concluded that empowering Registered Nurses in the nursing role and helping them find ways to best organise the work on their own unit and give feedback to the rest of the care staff will be important in any future study. However, the finding from the pilot study (Blekken et al., 2015c) was equivocal because the intervention made little impact to reduce FI and changes in the rates of FI were not sustained after the intervention period.



Fecal incontinence in the elderly: epidemiology and management (Wald, 2005) Suggests management is most effective when underlying causative factors are addressed. Links constipation and FI, noting overflow incontinence most common in physically or cognitively impaired patients who are institutionalised or bedridden.

Book chapter entitled 'Incontinence in the frail elderly' in *Incontinence* (Rockville *et al*., 2005): FI-specific section highlights need to manage both UI and FI as they often co-exist, establish bowel continence status by direct questioning, observation and case finding and need to be sensitive to social and cultural barriers around FI. Notes the large variation in FI prevalence reported.

Management of FI in adults: Clinical Guideline 49 (NICE, 2007) and Summary of NICE Guidance (Norton *et al*., 2007): Covers all adults so a need to extrapolate for older people with dementia (who fall in high-risk groups). Details what *should* be done but not how.

Dementia Quality Standard (NICE, 2010): Very high-level guidance. Continence not specifically considered but could be interpreted as referred to under assessment and personalised care plan, and non-cognitive symptoms and behaviour that challenges.

Diagnosis and Management of FI in the Elderly (Laing, 2009): A very biomedical review asserting the importance of full medical assessment, patient history and fairly invasive clinical investigations and noting the link between constipation and overflow FI. But no mention of dementia.

Geriatric Fecal Incontinence (Lykkeslet *et al*., 2014): Suggests physical and environmental factors may be contributing to FI in patients with dementia. Recommends medical assessment for all patients with FI and that habit training most benefits patients with cognitive impairment.

National Audit of Continence Care: Adherence to NICE Guidance in Older Versus Younger Adults with FI (Harari *et al*., 2014): Audit of adherence to NICE guidance on management of FI across all adults. Shows deficits in documented assessment, diagnosis and treatment for adults with FI, particularly older people.

Management of FI and constipation in adults with central neurological diseases (Coggrave *et al*., 2014): Found limited evidence for recommending any interventions. None of the trials are in people with dementia.

Book chapters entitled 'Focus on older people 'and 'Down, down and away! An overview of adult constipation and FI', in *Promoting Continence: A Clinical Research Resource* (Edwards *et al*., 2003; Getliffe and Dolman, 2003

Urinary and FI and dementia (Bravo, 2004): Focus on assessment and need to 'identify the underlying pathogenic mechanism'. Lists possible interventions from basic (e.g. type of clothes, environmental modifications) to sophisticated (e.g. biofeedback, surgery).

Fecal incontinence in older patients (Akhtar and Padda, 2005): Focus on frail older nursing home patients, 'who require an individualised approach, which should be minimally invasive and cost-effective.' Notes overflow FI due to faecal impaction common scenario in this cohort of patients.

Fecal incontinence – A review (Bellicini *et al*., 2008): Though not specifically older people focused they note that FI is 'predominantly a disease of the elderly of institutionalised patients.' Article objective – to raise awareness as: 'Proper diagnosis and knowledge of treatment options may benefit the quality of life.

Update on the Management of Constipation in the Elderly: New Treatment Options (Rao and Go, 2010): 'Elderly patients, especially those with advanced dementia in nursing homes and those on opioids for palliative care, require an individualized approach for the treatment of constipation.

Fecal Incontinence in the Elderly (Shah *et al*., 2012): Seems to suggest colostomy would be appropriate treatment option for less mobile cognitively impaired patients as it 'provides ease of defecation and hygiene. For care givers of such patients, a colostomy offers more scheduled bowel care, reducing caregiver burden and stress.

Faecal Incontinence: NICE Quality Standard 54 (NICE, 2014): Recommend a focused baseline assessment and first-line treatment is conservative management. Considers limited mobility and cognitive or behavioural issues as subgroups.

Managing Faecal Incontinence in Specific Groups (NICE, 2014). For people with cognitive impairment recommends behavioural and functional analysis but only after initial management if that has failed.

Figure 5.1: Example of FI literature over time (Goodman et al. 2017; page 28)

5.3 Guidance and review articles relevant to the management of faecal incontinence

The current Clinical guidelines of the United European Gastroenterology and European Society for Neurogastroentrology and Motility (Savarino et al., 2022) and the National Institute for Health and Care Excellence (NICE) (2007) guidelines on management of FI in adults are biomedically driven, with limited acknowledgement on how to implement continence care. For example, the international guidelines make no provision for providing bowel care to care home residents with underlying dementia (Savarino et al., 2022). Similarly, the NICE guidelines recommend careful examination of the anorectal region in settings some of which have limited access to clinicians (National Institute for Health and Care Excellence (NICE), 2007b, National Institute for Health and Care Excellence (NICE), 2014). The guideline covers all adults, thus making it difficult to extrapolate for older people with comorbidity such as dementia in care homes. A search on the Cochrane systematic reviews database for interventions on prevention and treatment of FI in adults found no randomised controlled trials (RCTs) focusing specifically on older people living with dementia in care homes (Coggrave et al., 2014, Maeda et al., 2013, Norton and Cody, 2012) and Musa et al. 2022 (submitted).

The evidence sources as aforementioned emphasise the importance of assessment, nutrition, hydration, and the diagnosis of faecal impaction. The underlying narrative being that clinical assessment is essential, but how this should be achieved lacks detail, particularly in care home settings for people living with dementia. The lack of robust bowel care, especially care that incorporates the care home residents' characteristics such as frailty and dementia, as well as the care home staff work routines, and the care home environment necessitated a realist synthesis (realist review) to theorise putative contextual factors that need consideration when developing a bowel care intervention for older people living in care homes.

A summary of findings from the realist review (the FINCH review) is outlined in the next section.

5.4 Summary of the FINCH programme theories or explanatory framework

A realist synthesis of evidence on managing 'faecal incontinence in people with advanced dementia living in care homes' (FINCH review) reported a set of programme theories of how different interventions support (or do not support) the reduction and management of FI (Goodman et al., 2017). The review was conducted to (i) identify which interventions could potentially be effective, how they work, on what range of outcomes (i.e., organisational, resource use and patient's level of care) and for whom (or why they do not work); (ii) establish what evidence there is on the relative feasibility and (when appropriate) cost of interventions to manage FI (Goodman et al., 2017). Two of the FINCH reviewers are supervisors of the PhD candidate.

The FINCH review (Goodman et al., 2017) draws together evidence from different strands of research to inform interventions that address the realities of working in and across complex overlapping systems of care. For example, it sought evidence on the physiology and management of FI (and UI) in ageing populations and those living with dementia in care homes, and the relative availability, acceptability, and efficacy of different types of incontinence products. The review also provides a conceptual basis to build a theory-driven intervention collaboratively with stakeholders (care home residents, residents' relatives, care staff, and care home commissioners). The importance of this is three-fold: firstly, there is evidence that interventions which are theoretically driven are more successful compared to those that are not based on theories (Michie et al., 2011). Similarly, studies which are developed in collaboration with stakeholders have proved to be successful in intervention development (McCloskey et al., 2011, O'Cathain et al., 2019). Secondly, the FINCH review had a strong patient and public involvement and engagement (PPIE) component which is believed to improve the relevance, quality, and impact of the work (Gray et al., 2021, Price et al., 2018). The reason behind such beliefs is that employing PPIE means that the research is carried out "with" or "by" members of the public rather than "to", "about", or "for" them (Hoddinott et al., 2018). Benefits of including research participants in developing research design and delivery include opportunities for the participants to contribute to setting research priorities, develop more user-focused research objectives, and improve trajectories that impact outcomes (Harris et al., 2018). Thirdly, it has been found that studies which are developed in collaboration with participants are more likely to be successful in terms of uptake compared to those that are imposed on participants (McCloskey et al., 2011).

From a scoping literature review, the FINCH review authors identified a series of barriers and enablers to conducting a bowel care intervention among older people living with dementia in care homes (Figure 5.2). The reviewers then formulated linked statements known in realist methodology as 'if-then statements' (Table 5.1) to provide them with an overview of specified context and mechanism on the reduction and management of FI in older people living in care homes. For example: ***If*** faecal incontinence (FI) is a result of a functional reason (e.g., access and ability to get to the toilet), ***then*** a suitably adapted environment and staff on hand to assist as needed will reduce FI episodes; and, ***if*** staff experience a supportive working environment, ***then*** residents will experience less FI and be more continent.

The reviewers did not limit their accounts to only those expressed in the literature, but also held a research management team (RMT) meeting, recognising that there were more to contexts and mechanisms to be explored within the care home setting. At the RMT meeting, attendants that included major experts in the field of continence care and care home research in the UK were asked to draw on their expertise to articulate: (1) The dominant approaches and assumptions that informed current thinking about what supported (and how) the reduction and management of FI; and (2) important outcomes and how impact was measured (Goodman et al., 2017). The reviewers also conducted five stakeholder group interviews with a purposively selected sample of stakeholders (e.g., care home managers, resident representatives, academics and practice educators, clinicians with a special interest in FI and continence specialists, commissioners, and providers of continence services) to complement the expertise provided the RMT members.

The reviewers then used a theory driven approach to articulate how particular contexts (C) or resources, have prompted certain mechanisms (M) or responses by those providing and receiving care led to the observed outcomes (O) (Appendix 13). The Context-Mechanism-Outcome (CMO) configurations do more than describe barriers and enablers; they help to understand what is going on in interventions and enable theorising how interactions among the environment, the people, and the resources may result in different patterns of outcomes (Gilmore, 2019, Pawson and Tilley, 1997, Wong et al., 2016).

A summary of the FINCH programme theories is presented in Table 5.2 below. The FINCH review proposed six broad theory areas that could explain how to improve continence care for people living with dementia and FI in care homes. These were as follows: (1) Clinician-led support, assessment, and review; (2) ongoing teaching, review, and feedback to care staff on how to reduce and manage FI; (3) addressing the causes and prevention of constipation; (4) interventions that reflect the degree of cognitive and physical capacity of the resident; (5) common understanding of the potential for recovery and reduction of FI; and (6) integrating care for people living with dementia and FI into everyday work patterns of the care home and staff (Goodman et al., 2017). A detailed description of each contextual factor and corresponding programme theory is presented in Table 5.2.

The FINCH review concludes by recommending that future interventions take account of how the presence of dementia affects the behaviours and choices of those delivering and receiving continence care within a care home environment (Goodman et al., 2017).

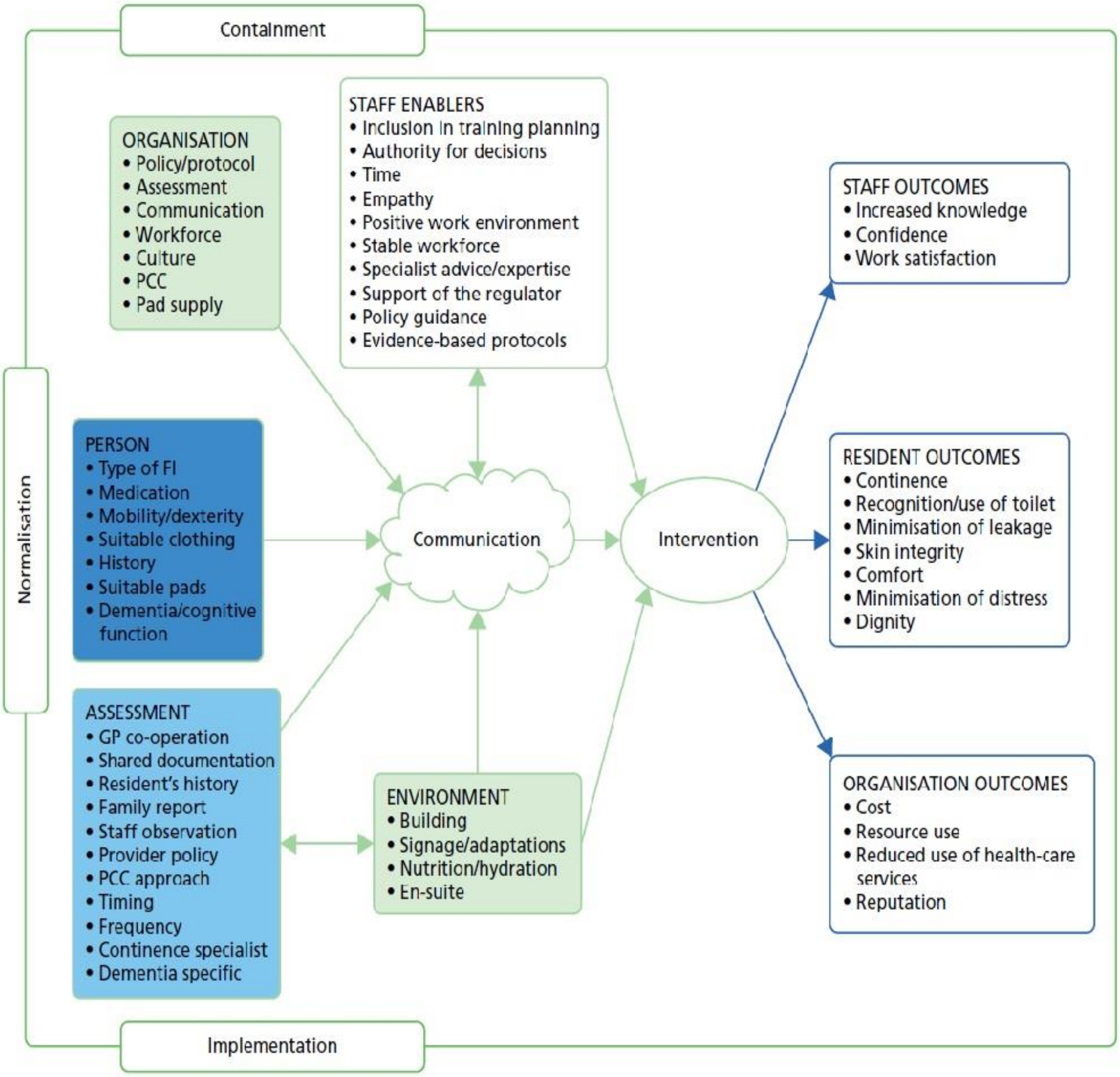
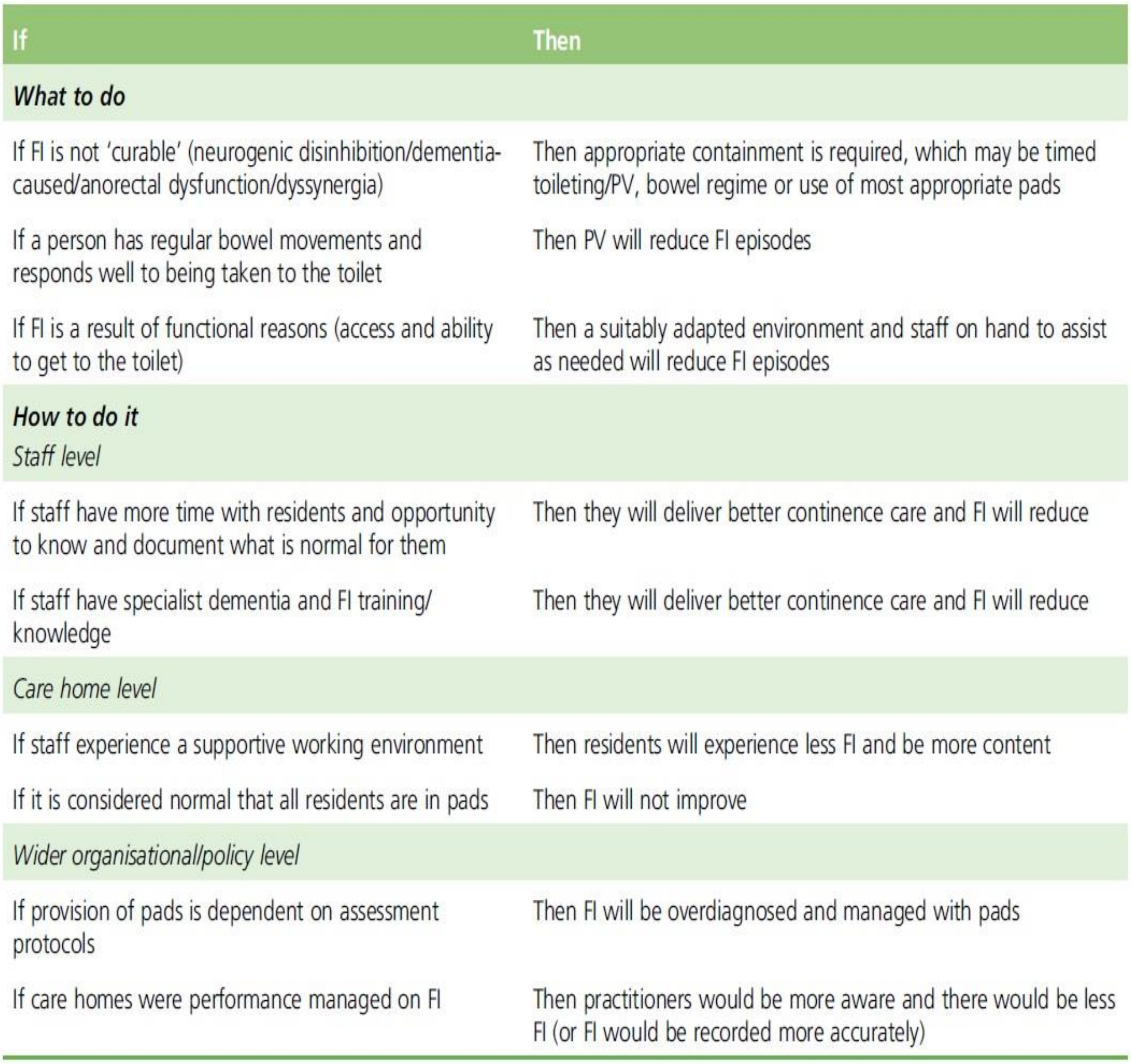


Figure 5.2: Barriers and enablers for FI intervention (Goodman et al. 2017, p.26)

Table 5.1: FINCH ‘If-the-statements’ (Goodman et al. 2017, p.25)



If	Then
What to do	
If FI is not ‘curable’ (neurogenic disinhibition/dementia-caused/anorectal dysfunction/dyssynergia)	Then appropriate containment is required, which may be timed toileting/PV, bowel regime or use of most appropriate pads
If a person has regular bowel movements and responds well to being taken to the toilet	Then PV will reduce FI episodes
If FI is a result of functional reasons (access and ability to get to the toilet)	Then a suitably adapted environment and staff on hand to assist as needed will reduce FI episodes
How to do it *Staff level*	
If staff have more time with residents and opportunity to know and document what is normal for them	Then they will deliver better continence care and FI will reduce
If staff have specialist dementia and FI training/knowledge	Then they will deliver better continence care and FI will reduce
Care home level	
If staff experience a supportive working environment	Then residents will experience less FI and be more content
If it is considered normal that all residents are in pads	Then FI will not improve
Wider organisational/policy level	
If provision of pads is dependent on assessment protocols	Then FI will be overdiagnosed and managed with pads
If care homes were performance managed on FI	Then practitioners would be more aware and there would be less FI (or FI would be recorded more accurately)

Key: FI = faecal incontinence; PV = prompted voiding

Table 5.2: FINCH Programme theories

Theory area	Theory assumptions
1. Clinician-led support, assessment and review will achieve observable improvements in FI.	This theory reflects the assumptions and training of clinicians (i.e., doctors, nurses and allied health professionals). Clinician-led assessment and ongoing support and review (C) informed by the use of jointly agreed approaches to the promotion of continence and alternatives to the use of pads (C) will achieve observable improvements in continence and resident well-being (O). The assumption is that the involvement of clinicians is key because care home staff do not have the authority or expertise (C) to be able to complete an assessment, particularly digital rectal examination, diagnosis of diarrhoea or drug review. When clinicians take a lead, care staff are confident (M) to accept (M) the delegated responsibility of assessment and management and the shared communication and review of residents increase staff awareness and involvement in continence care (M). Care home staff observe and document changes in the resident and this is fed back into the assessment/review process, and this reinforces (M) practices that support effective continence care (O).
2. Ongoing teaching and feedback for staff that involves care home staff in planning, action, review and implementation [e.g., Plan Do Study Act (PDSA)] will achieve positive continence-related outcomes.	This expresses the viewpoint that giving staff access to the appropriate training, education and facilitation will result in a change in practice (C). The mechanisms are that knowledge feedback and review (C) triggers changes in how staff recognise and interpret (M) residents' continence needs, their confidence (M) and how they work. The assumption is that this will lead to improved continence care (O). This theory is important to consider as so many care home interventions employ a training/education/facilitation approach.
3. Dealing properly with constipation in older people with dementia in care homes will ameliorate a significant proportion of FI as it is laxative induced or overflow FI due to constipation and impaction.	This area posits that a focus on the recognition, treatment and management of constipation (C) will prompt (M) staff to review residents' medication management, fluid and nutrition intake, bowel function and activities (C) that reduce the risk of constipation, such as exercise, communication strategies that encourage (M) the resident to ask to be willing to engage and regular toileting leading to appropriate containment and reduction of FI and resident discomfort and pain (O).
4. Interventions that take account of the history, preferences and wishes of the person together with acknowledgement of the degree of cognitive and physical capacity of	This area encapsulates the PCC approach to care. It assumes that if the resident, their history, their normal bowel patterns and their signals for needing the toilet are known (C) and staff are able to document and review in collaboration with a clinician assessment and family input (C) this means staff conceptualise continence care as unique to the individual resident (M) with the result that there is more dependent

the resident (individualised care) will reduce FI.	continence rather than FI (and UI) as well as outcomes that are consistent with the minimisation of distress and promotion of comfort (O).
5. Establish a common understanding of the potential for recovery, reduction and management of faecal incontinence for people with dementia will result in attempts to reduce FI.	This area addresses and seeks to militate against beliefs of therapeutic nihilism (the belief that nothing can be done and therefore nothing should be attempted). In its place a belief and value system is advanced about the residents' potential to maintain or improve functional abilities even when the trajectory is one of deterioration (expressed in staff training, documentation, language of care and handover) (C), and that it is possible to ameliorate FI in residents living with dementia, will mean that staff will be willing to engage and learn about what is causing the FI and attempt interventions (M) to promote continence and the management of FI are put in place (O).
6. Making FI care integral to the everyday work pattern and environment (i.e., 'fit') will reduce FI.	This argues that even if staff know about managing FI (C) and know about person-centred care practices for people with dementia (C), their capacity (C) to implement them will depend on how it fits (M) with the everyday work pattern and environment. A number of different contexts (knowledge of FI, knowing the person, appropriate staffing levels, availability of clinical expert input – geriatricians/GPs/continence nurses, belief continence can be improved and physical environment) will trigger 'doing the right thing' (M) and result in less FI and, most likely, dependent continence (O). These contexts may trigger other mechanisms, such as 'risk aversion' and 'pre-emptive pad use' that will not result in the desired outcomes. This area incorporates the ideas of staff balancing, juggling and making 'trade-offs' in their everyday practice.

Source: Goodman et al. (2017), p35-36

5.5 Authors' reported limitations of the FINCH review

The FINCH review is a realist review which tested emergent findings with stakeholders including the study steering committee, those with direct experience of commissioning and providing care in care home settings, clinical experts in care of older people living with dementia and family members who had supported relatives living with FI. The evidence from the review on clinical and functional approaches to the reduction and management of FI in care homes is somehow equivocal due to lack of direct evidence on FI (e.g., evidence was extrapolated from studies not on FI, but on person-centred care and dementia). The authors found very limited direct evidence about FI and how having dementia impacts continence care within care home setting. Although clinical assessment, knowledge of the causes of FI, including nutrition, hydration constipation and pharmacological, and behavioural therapy may be necessary in providing continence care to older people living with dementia in care homes, this may not necessarily be sufficient to achieve a change in frequency of episodes of FI.

While the programme theories proposed by the FINCH review provide a comprehensive account of what approaches are likely to contribute to the reduction and management of FI, their underlying theoretical assumptions and the evidence that supports or negates these approaches remain some key questions unanswered, among them:

- The lack of connection observed between continence research and dementia care; that is, the finding that no specific interventions developed or tested in the continence literature investigate dementia and FI beyond considering dementia as a risk factor for FI.
- The work on toileting problems and person-centred care was useful but needs to be operationalised in terms of the challenges that arise around resistance to care and helping someone living with dementia use the toilet and other continence aids.
- The lack of evidence about the extra hours and resource required for toileting interventions and how this informs care home business models.
- The wider care home research literature confirms that care home working is often organised according to tasks that need to be completed.

- Applicability of the findings to UK care homes amid limited evidence from the UK setting on supporting continence care in care homes.

Realists believe that programmes are theories in action and that the theories are often incomplete, implicit, or unconscious because different stakeholders may hold very different theories about whether, how, or why a programme works (or not) (Punton et al., 2020). Realists also hold that no intervention works in the same way for everyone, all the time, but will have very different effects on different people in different contexts (Wong et al. 2016) because programmes are inherently complex interventions introduced into complex social systems (Pawson, 2013). For more information on realist approaches, and how they are applied in this thesis, see Chapter 6.

To operationalise the proposed FINCH programme theories necessitates, therefore, further testing and refinement with care home stakeholders in practice. To do this, the PhD candidate aimed to carry out stakeholders' engagement to test, reaffirm or refute (where the evidence exists), and refine (where possible) the proposed programme theories (Chapter 6). Doing so will enable the PhD candidate to reframe continence care as person-centred care, embedding a multicomponent intervention that values and supports care home staff, as well as fits within routines of the care home.

Following testing and/or refinement of programme theories, intervention modelling will be carried out in collaboration with the care home stakeholders as recommended in the revised Medical Research Council (MRC) guidelines (Craig et al., 2008, O'Cathain et al., 2019).

5.6 Other limitations of the review

Crucially, the evidence did not address the detail of the process of care, or insights as to the ways in which care staff, clinicians and managers constantly negotiate the trade-offs between different resident, care home and staff priorities. Although all stakeholders in FINCH (Goodman et al. 2017) highlighted how distressing FI could be for both residents and staff and how important it was to know the resident, there were differences in emphasis among different groups. For example, doctors focused on the issues such as “regular assessment” and nutrition and hydration, whereas direct carers and family focused on approaches that stressed knowing the resident’s biography, and that promoted empathy and clarity/leadership within the care home.

The FINCH review developed a set of six potential middle-range theories and their possible CMOs to make explicit certain underlying assumptions (Table 5.2 above). However, there are some assumptions that require further investigation, among them include:

i) Whether by making sure residents get assessed by a clinician can reduce FI episodes.
ii) Whether staff training can improve continence care and lead to reduction of FI episodes among residents.
iii) Whether by addressing constipation and impaction, FI among residents can improve.
iv) Whether it is possible to implement person-centred care amidst competing care home workloads.
v) Whether by addressing nihilism about FI among staff (the fact that many people believe incontinence is inevitable among older people living with dementia in care homes), continence care can be improved to lead to reduction in FI episodes among residents.
vi) Whether by incorporating FI care with the everyday workflow and patterns of the care home can lead improved continence care that will translate to reduction in episodes of FI among residents.

5.7 Chapter summary

This chapter has given a snapshot of the FINCH review to enable readers understand and appreciate the theoretical basis for this thesis. The chapter set out key difficulties in care homes continence research, which the FINCH review seeks to remedy by proposing six programme theories. In the next chapter, the PhD candidate consults with care home stakeholders to confirm and/or refine the FINCH programme theories, considering that most of the evidence that underpins the FINCH programme theories derived from a wider care home literature, and from different geographical settings, making extrapolating findings difficult.

Chapter 6: A realist evaluation to explore FINCH programme theories

The aim of this chapter is to explore how FINCH programme theories (Goodman et al., 2017) could inform a bowel care intervention for care home residents. Bowel care (continence care) is invariably delivered by the lowest-paid frontline care staff in care homes. Understanding how their contribution affects uptake of practices that are likely to be beneficial (e.g., assessment, working with clinicians, regular toileting) is key to successful implementation of an intervention. The chapter describes consultations with care home stakeholders (care home residents, residents' family, care home staff, care home managers, and a commissioner) to test the FINCH programme theories' resonance and relevance to their work and to increase understanding of which programme theories could be included in the development of an intervention to reduce FI among older people living with dementia in care homes. This builds on realist evaluation approaches (Pawson and Tilley, 1997) that aim to provide explanatory accounts about how context dependent interventions and their outcomes are likely to work (or not) (Fletcher, 2017, Gilmore, 2019).

6.1 Background

The increasingly complex care needs of older people living with dementia and dying in care homes has led to a proliferation of guidelines, procedures, treatments, technology, or programmes, many of which have limited impact on health service delivery and health outcomes (Majid et al., 2018). Guidelines are not enough to effect change in practice and it is estimated that approximately two-thirds of health services research studies fail to translate into meaningful patient outcomes across multiple contexts (Damschroder et al., 2009). Some reasons why most of these studies have failed are explained in Chapter 4.

There are few intervention studies which have been conducted to reduce FI among older people living in care homes (Buswell et al. 2017). There have been some attempts to develop a multicomponent intervention to manage FI among older people living in care homes, but so far, those interventions have been of limited success in reducing episodes of FI (Blekken et al., 2015, Schnelle et al., 2010). These findings are consistent with a recent Cochrane systematic literature review led by the PhD candidate, which found lack of evidence of the most effective interventions to reduce frequency of FI episodes in older people living in care homes (Musa et al. 2022 [submitted]). The limited success of interventions for FI may be explained by the failure of those interventions to consider the complexity of contexts of the care environment and reasons for incontinence among residents (Goodman et al., 2017). Observational studies and trials have demonstrated minimal acknowledgement or adaptation of approaches to the individual care home resident, or his/her environment, and no account had been taken of the impact of comorbidity (e.g., impact of dementia on incontinence) as found in the Cochrane systematic review (Chapter 3). Crucially, dementia has consistently been recognised as a risk factor for FI, but no study has taken into account how the dementia affects a person's ability to recognise the need to find to a toilet, go to toilet, and/or remember how to use a toilet (Goodman et al., 2017, Musa et al., 2019). This is also true in the recent randomised control trial of dependent older people living in care homes [reported as nursing homes] in France, published after the review and development of the intervention in this thesis (Seigneurin-Hérissé et al., 2022). Although the study found that a daytime person-centred bowel programme significantly reduced frequency of bowel movements at night (Seigneurin-Hérissé et al., 2022), it did not account for how dementia or impairment in activities of daily living affected continence in individual residents.

6.2 THE STUDY

6.2.1 The realist evaluation questions, aims, and objectives

The questions for the realist evaluation are:

i) Do the FINCH programme theories offer plausible explanations to the stakeholders about what works and what needs to be in place when supporting and managing the care of older people with dementia and FI resident in care homes?
ii) What do stakeholders consider as valuable continence outcomes?

The aim of this phase of the thesis is to test and/or refine the programme theories proposed by the FINCH review (Chapter 5) through stakeholders' collaboration. As realist programme theories are theories in action that require refinement, consulting with stakeholders on what programme theories work (or not) in managing FI before developing an intervention is important (Westhrop, 2018, Wong et al., 2016).

The objective of this realist evaluation is to enable development of an evidenced-based, theory-driven intervention that will be acceptable (and sustainable over time) by the care home stakeholders.

6.2.2 Design

This phase of the thesis followed realist evaluation approaches (Pawson and Tilley, 1997). The rationale for using realist evaluation has already been provided in Chapter 4. Crucially, as this chapter focuses on theory testing and refinement, realist evaluation approaches herein are interested in causalities that reflect what triggers different responses that lead to different outcomes when providing care for older people resident in care homes with dementia and FI. The evaluation methods and reporting here follow the RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) guidelines (Wong et al., 2016).

6.3 Setting/Participants

This study was conducted in five care home units (out of six care home units) within a single care home in England, the United Kingdom. One of the units was not included because it provided respite only care. The care home provides accommodation and nursing care to older people. It provides beds for up to 215 older people across six self-contained units. There is a total of 279 employees of the care home: care staff (n = 257); activities/engagement personnel (n = 9); therapists inclusive of physiotherapists, occupational therapists, and moving and handling advisor (n = 11); dietician (n = 1); and pharmacist (n = 1). There is an onsite General Practitioners' office and a pharmacy. A General Practitioner visits each unit fortnightly to assess the care home residents. Each unit of the care home has a Unit Manager who runs the day-to-day activities of the residents and the care staff (Healthcare Assistants and Registered Nurses). The shifts are typically run by 2 Registered Nurses (RNs) and 5 Healthcare Assistants (HCAs) during the day, and one RN and 3 Healthcare Assistants (HCAs) during the night. The day shift runs from 07:00 to 19:00 (although some staff work half shifts, either from 07:00 to 13:00, or 13:00 to 19:00), and the night shift runs from 19:00 to 07:00.

Prior to the stakeholders' consultation to test and/or refine the FINCH programme theories, the PhD candidate as a period of familiarization spent a total of thirteen months undertaking voluntary work, supporting residents one day a week in the care home. During this time, the PhD candidate worked as healthcare assistant (HCA). He supervised residents in communal areas, moving residents between communal areas and residents' bedrooms, supported residents with feeding during mealtimes, and assisted taking residents to toilets and changing incontinent pads when it was necessary. This prolonged engagement with the care home enabled him to build up a rapport with the stakeholders and to understand the care home culture and routines. This in turn influenced how focus group discussions and semi-structured interviews were scheduled and conducted (e.g., during staff break times to avoid disruption of the care home routines).

6.3.1 How the study site was selected

The study site convened a Care Governance Workshop on 19th October 2017 to discuss what could be done to improve care. Prior to the workshop, the care home had carried out a survey, a summary of findings is presented in Table 6.1 below. Among other improvement measures, the care home decided to invite professionals with expertise in managing incontinence. It was against this backdrop that the care home invited the PhD candidate's primary supervisor. The PhD candidate and his primary supervisor attended the next care home workshop (Quality Improvement Workshop) on 09th November 2017. It was during that workshop that the care home stakeholders were informed that coincidentally there was a PhD research study planned to address faecal incontinence in care homes. The care home staff and managers attending the workshop enthusiastically agreed to be the study site for this PhD research.

Table 6.1: Summary of challenges faced by the care home prior to the study

	Unit 1 (n = 38) ND	Unit 2 (n = 22) ND	Unit 3 (n = 42) R	Unit 4 (n = 38) D	Unit 5 (n = 27) N
Urinary incontinence	34	22	16	33	27
Dementia	34	22	10	33	15
Doubly incontinence	34	22	5	20	27
Immobile/bed or wheelchair bound	16	21	3	4	26
Swallowing problems/needing assistance to eat	23	20	1	6	13
Iron & Lactulose used	5	1	3	13	15
Antidepressants and/or sleeping tablets	14	3	3	3	10
Aggressive behaviour/aggitation	11	4	2	10	2
Pressure scores	4	2	4	3	5
Receiving one to one care	10	1	0	1	3
Smeared faeces	1	1	0	1	0

Key: ND = Nursing Dementia; D = Dementia; N = Nursing; R = Residential; n = Number of residents

6.3.2 Participant recruitment

All potential care home residents and their family, as well as care staff working permanently in the care home were invited to take part in this phase of the study. The Unit Managers identified potential residents and family members, first informally contacting them about the study, making sure to ask for their permission to be contacted by the PhD candidate. Potential residents and family members who did not wish to be contacted by the study team were not contacted. For those that agreed, the PhD candidate sent out a participant information sheet (PIS) (Appendix 14), with a simplified version for people living with dementia (Appendix 15) and the option for consultees for people who could not provide informed consent (Appendix 16). For those that could provide informed consent, there was also a letter (Appendix 17) inviting the addressee to a meeting if he/she wished to participate in the study. To aid care staff recruitment, the PhD candidate met with Unit Managers and other senior staff of the care home and made a PowerPoint presentation of the research study. He also attended staff meetings on the units to inform the staff about the study and handed out PIS to potential participants. This enabled those who expressed an interest to contact the PhD candidate independently of the care home Unit Managers.

6.3.3 The inclusion and exclusion criteria during stakeholders' consultation

Table 6.2 contains the inclusion and exclusion criteria for the stakeholders' consultation phase of the thesis.

Table 6.2: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Care home residents aged ≥ 65 years. • Residents capable of giving valid informed consent; for those lacking capacity to consent, a consultee's permission will be sought. • Relatives of care home residents • Direct care staff employed by the care home where the study is taking place* • Commissioners, Unit Managers, Pharmacists, Physiotherapists, Nurse Practitioners, dieticians, and occupational therapists of the care home where the study is taking place.	• A comatose resident (or resident on end-of-life pathway) as identified in care notes. • Other personnel working at the care home through a third party (e.g., agency staff) do not meet the inclusion criteria.

*Direct care staff is defined herein as those who provide incontinence care for older people in care homes (i.e., registered nurses, care assistants)

6.4 Ethical considerations

Ethics approval for this study was granted by Yorkshire & The Humber - Bradford Leeds Research Ethics Committee, UK (REC ref: 19/YH/0089; IRAS project ID: 244359) (Appendix 18) prior to recruitment. Before the focus group discussion and interviews, participants were informed about confidentiality. Written informed consent, and recording permission were received from all participants. The study protocol followed the Declaration of Helsinki (World Medical Association, 2013).

6.5 Data collection

In realist evaluation (RE), data collections (and data analysis) are theory-driven (i.e., it starts with hypotheses formation, followed by collecting and analysing data to test these hypotheses, and draws theoretical conclusions based on the findings). Data collection in RE involves iterative approaches (Bergeron and Gaboury, 2020) and these are sometimes by ways of qualitative enquiries (Jackson and Kolla, 2012) and quantitative data where possible

(Gilmore et al., 2019, Westhrop, 2018). During qualitative data collection within the evaluation (e.g., focus group discussions, in-depth or semi-structured interviews, and key informant interviews), it is important that evaluators also employ the realist interview technique, a collaborative form of theory refinement in which the interview is guided by the theories that require refinement (Gilmore et al., 2019, Manzano, 2016, Pawson and Tilley, 1997).

In realist evaluation, the subject matter of data collection is the researcher's theory and respondents confirm, falsify, or refine this theory. The researcher starts with teaching the respondent 'the particular programme theory under test' and then 'the respondent, having learned the theory under test, is able to teach the researcher about those components of a programme in a particularly informed way' (Pawson and Tilley, 2004).

The use of qualitative methods such as focus group discussions and individual interviews are believed to be suitable in a realists' approach (Gilmore et al., 2019, Manzano, 2016, Pawson and Tilley, 1997). The rationale is that understanding the participant role is predicated on the need to understand how he/she articulates what is happening and why. This informs the development and testing of theory. Therefore, it is recommended that this method of data collection follows realist interview principles to: stimulate reflection among participants; encourage them to clarify their thoughts; and help them to funnel information to identify underlying mechanisms (Bergeron and Gaboury, 2020, Greenhalgh, 2017). It is also recommended to explore the participant knowledge, and understanding of the programme (Greenhalgh, 2017, Manzano, 2016). The rationale for this is that during interviews and/or focus groups, theories are placed before the respondents for them to comment on with a view to agree or disagree, thus enabling programme theory refinement.

In this thesis, the PhD candidate adopted both quantitative and qualitative approaches to data collection to answer the research questions. A qualitative approach can help in the identification of contextually grounded explanatory mechanisms which could be difficult to obtain using only quantitative methods. It has shown to describe the process of change during an intervention, and how and why an intervention 'works' or 'fails' (Dalkin et al., 2015, Greenhalgh et al., 2009, Willis et al., 2018). It is the basis for RE that the choice of data collection methods should be theory-driven and that data collection methods should be purposely selected because the chosen methods should be able to uncover patterns and regularities about the programme (Manzano, 2016).

Interviews are important to build knowledge of variations in what happens in natural settings and this knowledge contributes to building, testing, and refining theories. Unlike generic qualitative interviews that tend to explore aspects and concepts of conversations, realist interviews are interested in investigating propositions (Manzano, 2016). The type of realist interview used in this research study is a semi-structured interview. In realist semi-structured interviews, exploratory questions are based on the programme evaluated and acts as instrument to draw out the propositions of the general inquiry. It covers the objectives of the study and provides information around services, specific arrangements and resources for specific users or teams, and other relevant resource issues (Manzano, 2016).

The PhD candidate also employed non-participant observation at the study site during the refinement of programme theories (Goodson and Vassar, 2011, Handley et al., 2019). Non-participant observation is a commonly used data collection tool (Greenhalgh et al., 2009, McGaughey et al., 2017). Data from observations potentially complement evidence from other sources, such as interview data (Wye et al., 2014), provide a record of naturally occurring events and interactions and may highlight disparities between reported practice and actual practice (Marchal et al., 2012). Recording contextual factors, such as work routines, environmental and social features, build understanding of the influence of structures and processes on the actions of healthcare staff and outcomes for patients (Walshe et al., 2011).

The iterative processes of data collection (e.g., beginning with existing knowledge from the literature, focus group discussion, semi-structured interviews, and non-participant observation, and often going back to participants to confirm events) helped identification of mechanisms that may enable (or refute) acceptability, sustainability, and potential scalability of a bowel care intervention. These iterative processes are illustrated by double arrows in Figure 6.1. The approaches adopted for programme theories refinement is in line with previous realist evaluations processes (Gilmore et al., 2019, Mukumbang et al., 2016), as it is presented in Figure 6.1.

As can be noted in Figure 6.1, the FINCH programme theories provide the basis for theoretical underpinning of the thesis which was tested through stakeholders' engagement.

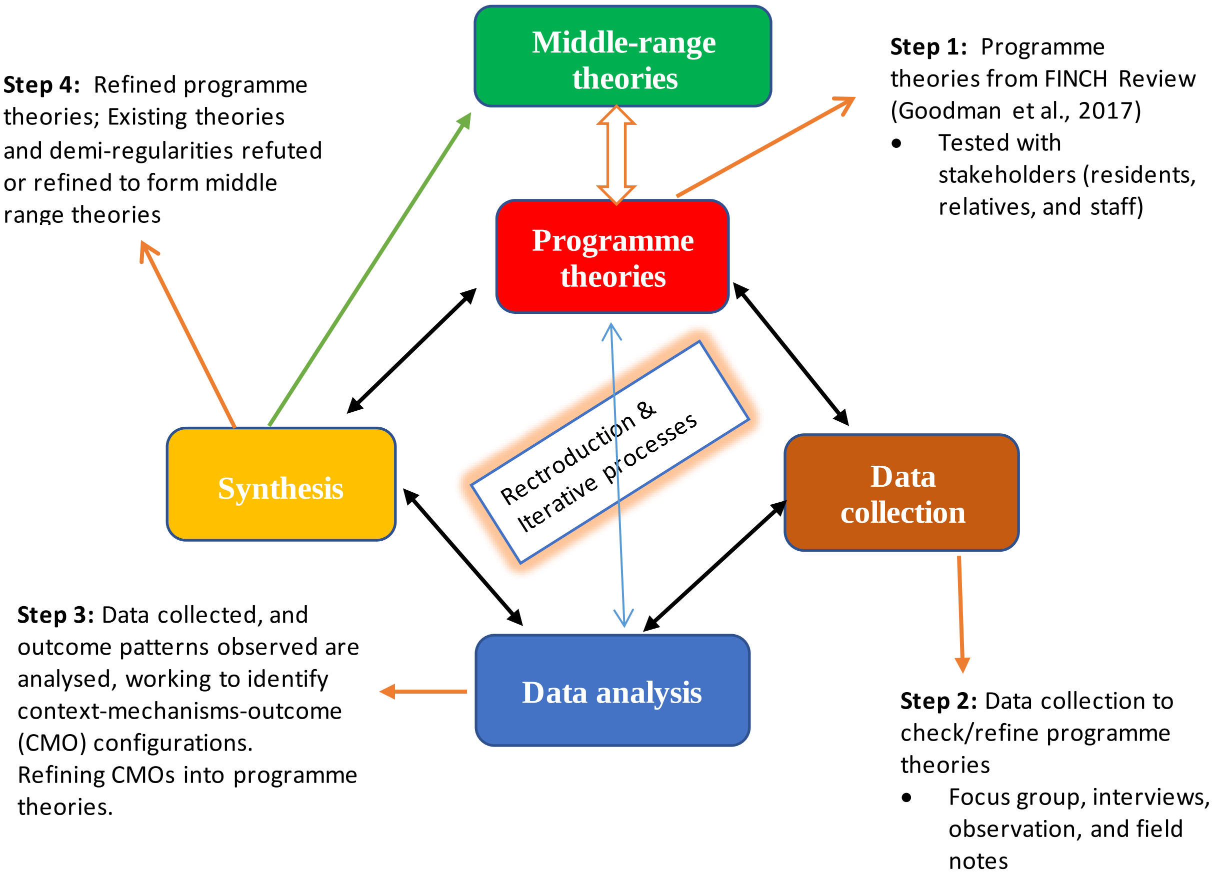


Figure 6.1: The realist evaluation processes, adapted from Rycroft-Malone et al. 2016

The data collection methods employed during this phase of the thesis were: focus group discussion (FGD), semi-structured interviews and non-participant observations. The questions used in the semi-structured interviews were based on findings from the FGD. First, the FGD was carried out and this directed subsequent semi-structured interviews with some participants that participated in the FGD. Murray et al. (2009) found that the use of repeating or serial interviews helped to uncover the complexities of individual situations by allowing the narrative to develop. The focus group guide (Appendix 19) was developed from findings of the FINCH review and two systematic literature reviews (Chapters 2 and 3) conducted by the PhD candidate. The semi-structured interview guide also derived from similar sources, but in conjunction with responses from the earlier FGD (Appendix 19). The topic guides of both FGD and semi-structured interviews tested the FINCH programme theories in terms of the stakeholders' explanations of how, and for who the FINCH programme theories work (or not) when providing bowel care for residents with FI and dementia.

Realist evaluation is an iterative process enabling the researcher to refine and revisit core ideas with participants. Therefore, the initial semi-structured interview guide was refined as new ideas or different interpretations were suggested to support realist ways of questioning (Appendix 20). The iterative process of refining interview guides continued throughout the interview process, guided by data analysis by the PhD candidate, and feedback from the care home stakeholders and the PhD candidate's three supervisors.

Consistent with realist interviewing, an open stance was maintained for all interviews, probing into emerging themes and seeking clarification when necessary (Maluka et al., 2011). Both the FGD and semi-structured interviews were audio recorded and later transcribed verbatim by an independent transcriber who was not involved in the study.

Focus group discussion (FGD)

First, an FGD with care home staff was conducted by the PhD candidate (MKM) and two of his supervisors (CN and RN). Both CN and RH are registered nurses. During the FGD, participants were asked questions such as: (1) "Can you tell me what you know about bowel care and faecal incontinence?", (2) "In your opinion, what may contribute to faecal incontinence in the resident that you are looking after?", and (3) "Is there anything you can do to reverse episodes of faecal incontinence in older person with dementia because one of the theories about bowel care says that people generally believe that nothing can be done to improve faecal incontinence in older people. Is that correct?".

Semi-structured interviews

The PhD candidate also carried out eight semi-structured interviews: two group interviews and six individual interviews, each lasting approximately 25 to 45 minutes. Only one resident was recruited during this phase of the study because most of the residents lacked capacity to consent due to underlying dementia or were judged by the care home staff as not well enough to engage in interviews.

In addition to the theory informed prompts, the semi-structured interview guides addressed some of the issues that arose during the FGD and reflected how respondents understood the issues. These focused on factors that facilitated or impeded continence care of older people living in care in general, and specifically those that are living with dementia. It encouraged an open conversation about the issues and different lines of thought about the topics. Some of the questions posed to the stakeholders during the initial semi-structured interviews included: (1) Can you tell me what are some contributing factors of faecal incontinence? 2) How do you currently care for people with faecal incontinence in your care home/unit? 3) Can faecal incontinence be managed or treated from your experience in working with older people with faecal incontinence and dementia? (Appendix 19). These questions were later refined in line with realist approaches (Appendix 20) to help unravel the context and mechanisms require for bowel care. Questions were reframed to reflect the preoccupations of staff about risk and assessment and the challenges of personalizing residents' preferences when providing continence care, like:

- Do care staff have permission to carry out physical examination of a resident that is at risk of constipation or faecal incontinence? What happens when you think a resident is constipated? Is there anything that make you to ask other staff for help and/or to make referrals?
- Do you always incorporate resident's preference/choice/wishes into his/her care (including bowel care)? If yes, how? If not, why?
- How does dementia impact on a person's ability to engage with continence care (e.g., going to toilet)?

- What are some necessary conditions/things that need to be in place at the care home to make staff work towards improving faecal incontinence in people living with dementia?

Non-participant observation

During the programme theories refinement process, the PhD candidate carried out non-participant observations in the communal areas in the care home units. A non-participant observation is one of several data collection methods usually employed in realist evaluation (Handley et al., 2019).

The non-participants' observations were carried out during both formal interactions (usual care routines) and informal interactions (e.g., communication with care staff). The focus of observation was on how staff responded to residents' care needs (including bowel and dementia care) and what triggered staff response. To understand the reasoning behind a staff member's response to residents' needs in certain ways, the staff member was usually contacted immediately after the care routine for clarification. This facilitated real-time explanations from staff about the mechanisms driving their actions. For example, if a care assistant supported a resident to the toilet, he/she (the care assistant) would be asked how he/she knew that the resident needed toileting assistance (provided the resident did not request), and what would have happened if he/she did not provide the toileting assistance. Observations on the units were carried out based on an opt-out process (Caswell et al., 2015). The PhD candidate attended staff meetings and information about the non-participant observation was explained to the staff. Similar information was also shared with residents and their family members through the Unit Managers. All residents, residents' family members, and staff working in the care home units where the research study was taking place were informed that they could opt-out if they did not wish to be observed by the PhD candidate during the study. There was no opt-out during the study.

Handwritten field notes were documented immediately following observations and/or discussions to minimise recall bias. The PhD candidate did not develop an a priori topic guide for the non-participant observation, to enable coverage of emergent situations, and he did not use a structured approach to record his observations. Nevertheless, the observation was influenced by the PhD candidate's volunteer time at the care home, familiarity with the literature, and the emerging data from the FGD and semi-structured interviews. Although it was the PhD candidate's first time carrying out field observation for research (and would be considered a naïve observer on that basis), it must be acknowledged that he is a registered general nurse (RGN) and had previously worked as a HCA in care homes prior to gaining his qualification as an RGN.

The data from non-participant observation were used to either corroborate or provide conflicting perspectives of the proposed FINCH programme theories. The collection of data through FGD, semi-structured interviews, and non-participant observation during this study period established method triangulation, which strengthens internal validity.

6.6 Data analysis

Data analysis in RE requires moving back and forth between the programme theory and the data, to bring out elements of context and mechanisms that can explain outcomes (Bergeron and Gaboury, 2020). Although there exists guidance on principles of data analysis when undertaking a realist approach (Wong et al., 2017), an expanding literature suggests different ways data analysis has emerged (Gilmore et al., 2019, Salter and Kothari, 2014). While some authors have used thematic analysis (Moore et al., 2012), others have proposed analytical induction (Byrne, 2013), or a "retroductive" approach (Gilmore et al., 2019). Retroduction refers to unravelling "*hidden causal forces that lie behind identified patterns or changes in those patterns*" (Wong et al, 2017, p. 1). A retroductive process requires the use of one's common sense in conjunction with multiple data sources to test and refine programme theories (Wong et al., 2017).

In this study, the first four steps involved in Braun and Clarke (2006) thematic approaches were followed. First, the transcripts were read several times to become familiar with the data. This enabled generation of codes from the transcripts (Appendix 21), which were reviewed and redefined as summarised in Appendix 22. Coding of transcripts started immediately after the focus group discussion, with new data added to the analysis as it emerged. A deductive or theoretical (or 'bottom down') thematic approach was used to identify themes semantically (e.g., identifying themes within explicit meanings without looking beyond what the participants said) (Braun and Clarke, 2006). A deductive thematic analysis is used when a researcher begins analysis of the data with a set of themes that he expects to find based on prior research or theory (Crosley, 2021). A deductive approach, rather than inductive approach, was suitable given that this work was undertaken to refine a set of programme theories already developed by other researchers (as summarised in Chapter 5).

The data analysis process for the current realist evaluation followed the work of Rycroft-Malone and colleagues (Figure 6.2).

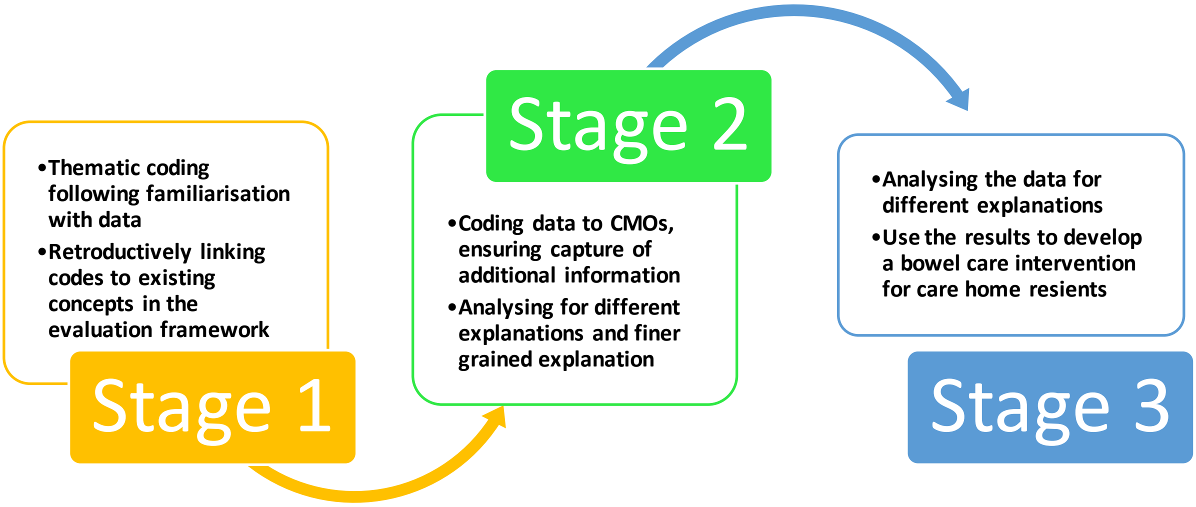


Figure 6.2: Data analysis stages in realist evaluation, adapted from Rycroft-Malone et al. 2016

Following the four steps of Braun and Clarke (2006) thematic approach, a series of “if-then” statements were developed as putative hypotheses (Table 6.3). These “if-then” statements helped to challenge the themes through further semi-structured interviews with the stakeholders.

Table 6.3: If-then statements from the data

Programme theories	If	Then
Clinical lead	i) If there is a clinical lead to carry out assessment (e.g., digital rectal examination) ii) If clinician takes a lead in review of residents iii) If there exists a shared communication between clinician and care staff	i) Then care staff may become confident to accept responsibility or delegated work (e.g., identifying residents at risk of bowel care). ii) Then care staff awareness and involvement in continence care may increase. iii) Then care staff may feel motivated to observe and document changes in the resident and this may be fed back into the assessment/review process, thus ensuring effective continence care.
On-going teaching	i) If care staff are given access to appropriate continence care training/education/facility ii) If care staff have specialist dementia and FI training/knowledge	i) Then care staff may be empowered to recognise and interpret residents' continence needs. ii) Then they will deliver continence care and FI will reduce
Dealing with constipation	i) If care staff know the underlying causes of constipation ii) If care staff manage constipation properly in older people with dementia	i) Then care staff are likely to take steps (e.g., review of bowel charts) to recognise residents at risk of constipation. ii) Then the proportion of laxative induced FI among residents will reduce.
Resident-centred care	i) If care staff are aware of residents' normal bowel patterns and signals for needing toileting assistance ii) If carers can make care plans in collaboration with residents' relatives and clinicians' input	i) Then this may trigger among care staff the need to keep accurate bowel record and to promptly response to individual resident when the need arises. ii) Then continence care may be individualised with the result that there is more dependent continence, promotion of dignity/comfort and minimisation of distress to the resident.
Common language	i) If care staff are made aware of a resident's potential to maintain functional abilities and to ameliorate FI (e.g., from documentations/handovers/training)	i) Then care staff will be willing to engage residents with activities, learn about the causes of FI, and to promote reduction of FI.

FI as CH routine	i) If care staff have knowledge about FI and person-centred care for older people with dementia ii) If staff experience a supportive working environment	i) Thein the care staff ability to translate their skills into practice will depend on whether their care home routines allow such practices. ii) Then residents will experience less FI and be more content

The themes were then organised descriptively using rectroductive approaches (Jagosh, 2020) based on suggested associations between different activities when providing continence care. The themes were aligned with the FINCH programme theories using direct quotations from the transcripts (Appendix 22). The realist evaluation concept of context-mechanism-outcome (CMO) configurations was employed to demonstrate how the data confirmed, differed, or provided more meaning to the theories (Table 6.4).

Analysis of the focus group and semi-structured interviews data was done simultaneously using the FINCH programme theories as a framework. The rationale for this was to build explanation for if and how the FINCH programme theories resonated with the care home staff, and to what extent an intervention based on the programme theories could fit into the care home routines. This approach is in line with Manzano's (2016) assertion that frontline practitioners should be first line of enquiry because they frequently see themselves as 'picking up the pieces' following top-down programme implementations and are good sources of information about programme barriers and unintended consequences.

Observation data were analysed separately using the same process as the one described for FGD and semi-structured interviews data. The findings of the observations are presented under relevant programme theories in the 'findings' section below. Observation data were used to assist in the decision-making process of programme theories refinement (to support or give an additional view).

6.7 Changes from the protocol in the evaluation process

Realist evaluation is an iterative process; therefore, adjustments were made to the study protocol in the light of emerging or new lines of enquiry. Key changes to the protocol are listed below:

i) Although it was initially planned to develop an intervention for all care home residents with a view of individualising the intervention to residents' specific needs, the focus of the thesis later changed to prioritise residents in the care home with dementia and history of faecal incontinence. The reason for this was to align focus of the thesis with the goal of the care home where the research study was carried out. During the focus group meeting with the care home staff, it became apparent that they were managing FI well for residents without dementia. The staff major concern was FI and constipation in residents with dementia – possibly due to the increased uncertainly about residents' behaviour. Nevertheless, considering that 80% of the care home population have dementia (Goodman et al., 2017), it was considered that an intervention tailoring bowel care to residents with dementia may later be extrapolated to the entire older people care home population, with some modifications to account for those without dementia.

ii) It was anticipated to recruit between 20 and 30 participants during this phase of the research study (Stakeholders' consultation). However, due to difficulty recruiting, the sample recruited for the stakeholders' consultation was twenty-three. The difficulty regarding staff recruitment arose from the eligibility criteria which excluded temporary care staff such as agency workers. During staff recruitment, several permanent staff were either on annual leave, or off sick. Additionally, Unit Managers were concerned about sending their staff out of the unit to attend focus group meetings. To enhance recruitment, an agreement with the Unit Managers was made to host one focus group meeting at about lunch time. Many invitation letters were sent out to relatives of residents to participate but none responded to the Unit Managers. To enhance recruitment of relatives, the managers advised that they would speak with relatives if any of them visited the care home. The PhD candidate was advised to be at the care home when they approached the relatives. It became apparent that most relatives visited the care home at about lunch time, and that at the time they visited, they were either too busy with their loved ones, or hurrying to attend other engagements. Therefore, a group meeting (rather than individual meetings) was agreed with the two relatives who agreed to participate in the study. The two relatives had previously received the invitation at their home addresses. Only one resident was recruited during this phase of the study because at the time of recruitment, residents either refused to participate in the study, could not participate due to cognitive impairment, or were too ill to participate.

iii) It was intended to carry out three Focus Group Discussions (FGD) – one comprising residents and relatives, the second comprising staff (Registered Nurses, Care Assistants, Unit Managers, Pharmacists, Physiotherapists, and Dieticians), and the third to comprise of unit managers (including senior staff within the care home). Each of the FGDs were anticipated to comprise of between five to eight participants, with each FGD lasting up to a maximum of 2 hours. However, due to poor recruitment compounded by over stretched care home routines, a single FGD with care home staff (inclusive of care assistants, registered nurses, Unit Manager, Pharmacist, Physiotherapist, and Dietician) was conducted.

6.8 Reflexivity and Rigour

Given the sensitivity of faecal incontinence, a participant relationship was established by listening and using a non-judgemental approach. The focus group discussion and interview questions were neutral and open-ended to enable participants to share their opinions.

Following rigorous methods throughout qualitative research is a way of establishing confidence in the findings (Thompson et al., 2022). The PhD candidate is aware of ongoing debate in the literature about how to ensure rigour in qualitative research (Mays and Pope, 2020, Reynolds et al., 2011). The strategies employed in this phase of the thesis combined two approaches – one by following the RAMESIS II reporting standards for realist evaluations (Wong et al., 2016), and two by ensuring rigour in four domains as in general qualitative studies: credibility (truth-value), dependability (consistency), transferability (applicability), and confirmability (Thomas and Magilvy, 2011, Thompson et al., 2022).

6.8.1 Credibility

Credibility, also known as truth-value, allows others to recognise the experiences contained within the study through the interpretation of participant's experiences (Thomas and Magilvy, 2011). The PhD candidate spent a total of 13 months proving voluntary services as a Healthcare Assistant (HCA) prior to the study. The prolonged engagement with the care home stakeholders enhanced familiarity with the study setting and built rapport, enabling elicitation of more in-depth information from the participants in this study. It also helped him to interview new participants who had the potential to add depth to the data to provide answers to the research question. The PhD candidate was also able to check his personal perceptions and predispositions as a former HCA (and now a Registered Nurse) and this helped him to be reflexive while he interviewed participants and carried out non-participant observations.

To further increase credibility of the study, the study protocol was developed. The study protocol contained focus group discussion and semi-structured interview guides which allowed focus and flexibility during the interviews. During data analysis, the focus group and interview scripts were read several times to familiarise with the discussions, before coding of script began. The findings from the data are presented using participants' words verbatim which demonstrates originality and credibility of data analysis processes.

6.8.2 Dependability

Dependability, also known as consistency, occurs when another researcher can follow the decision trail used by the researcher (Mays and Pope, 2020). In this study, dependability has been established by the PhD candidate clearly stating the aims and objectives of the realist evaluation, describing participants recruitment, how the data were collected and for how long the data collecting lasted, and the data analysis techniques employed. The PhD candidate undertook a week-long training in realist research methodology before he commenced the study.

6.8.3 Transferability

Transferability, also known as applicability, is the ability to transfer research findings or methods from one group to another, or how one determines the extent to which the findings of a particular inquiry have applicability in other contexts or with other subjects/participants (Thomas and Magilvy, 2011). To replicate this study, one should consider description of the study site and its workforce as provided above. It is the general position of the realist that an intervention that works in one setting may not work in another setting (or may even be harmful) because intervention implementations are context dependent (Pawson and Tilley, 1997, Westhorp, 2014). Similarly, findings from this realist evaluation cannot be transferred to other care settings in the absence of the contexts under which the study was delivered.

6.8.4 Confirmability

Confirmability, which is a degree of neutrality, occurs once credibility, transferability and dependability have been established (Thomas and Magilvy, 2011, Thompson et al., 2022). Throughout the study, the PhD candidate remained reflexive to maintain openness to the study and unfolding findings. Immediately following the focus group discussion and interviews, the PhD candidate made notes regarding his personal feelings and insights. Additionally, he made a conscious effort to follow, rather than lead, the direction of the interviews by asking participants for clarification of slang or metaphors.

6.9 Findings

For this phase of the thesis, twenty-three participants were recruited: 19/260 staff comprising of care assistants (n = 10), registered nurses (n = 4), unit manager (n = 2), pharmacist (n = 1), dietician (n = 1), and physiotherapist (n = 1); 1/214 resident, 2 family members, and a care home commissioner (a former geriatrician).

The data come from an FGD, 2 group semi-structured interviews (consisting of two participants each), 6 individual semi-structured interviews, and non-participant observations. The FGD lasted for one hour and twenty minute and was attended by 15 care home staff, including care assistants (n=9), registered nurses (n=2), unit manager (n=1), activities coordinator/physiotherapist (n=1), dietician (n=1), and pharmacist (n=1). The semi-structured interviews lasted from 25 min to 45 min) with staff members (2 registered nurses, a Unit Manager, 4 Care Assistants, and a former geriatrician/care home commissioner), a resident, and two relatives of residents. The non-participant observation sessions ranged from 2 hours to 5 hours (mean = 3.5 hours) to minimise the effect of blending into the background (Clissett et al., 2013). A total of 48 hours of non-participant observations were carried out over 12 observation periods, with 8 sessions completed on Wednesdays and 4 sessions completed on Thursdays.

Findings from the stakeholders' engagement is summarised in Table 6.4. The table demonstrates how the data support and/or provide further explanation for each programme theory, including new insights about the programme theories. How the data relates to each programme theory area is detailed in a 'box' immediately below the theory. Each box contains 'quotes' which are direct quotations from the data. The CMO configurations are then provided, without specifying the mechanisms which are reported in Table 6.4. The boxes with quotations are provided for easier reference. For clarity, the findings are reported in sequence of the research questions, using the FINCH programme theories as a framework. More detailed findings are provided under each of the programme theories, demonstrating where the evidence confirms or adds new knowledge or understanding.

Table 6.4: Findings from testing the FINCH programme theories with care home stakeholders

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT1: Clinical support, assessment, and review	EVIDENCE	**On-site GP and availability of Advanced Nurse Practitioner (ANP) for advice, review, and/or referral for immediate clinical input.** **FP4:** *"So, each unit has its own GP, so they get a visit once a week from their GP. So, any routine reviews would be referred … if I notice, for example, that someone has been omitting their laxatives for 2 or 3 weeks due to loose bowels, sometimes that does happen, I do flag up saying I think probably this needs to be reviewed."* [FGD]	1. Existence of GP (resource) 2. Staff feel supported and therefore make referral (reasoning)	**Earlier referral and detection of bowel problems (e.g., constipation/faecal impaction) by the clinician (ANP/GP)** CMO = Earlier referral and detection of bowel problems among care home residents (O) can be achieved by the clinician (C) when the care home staff have access to engage with and involve the clinician (M).
		MP2: *"We have the incontinence lead now in each unit that we will be having a meeting…. For residents who are experiencing faecal incontinence, with an underlying cognitive impairment, we'd not be able to stop that due to their conditions …"* [FGD] **MP1:** *"we can always refer to the GP or to our ANP. They will come to review and then we continue monitoring how the person goes."* [FGD]	1. Existence of incontinence leads/ANP/GP (resource) 2. Staff feel motivated or supported to carry out bowel care (reasoning)	
		Care home staff do not have the permission and/or the mandate to carry out certain clinical duties. **Respondent-2:** *"We are not…well I am trained to do it [rectal examination], but we are not allowed to do it here. We have the advanced nurse practitioners who are allowed to do those things. …when I started working here even when I was working in another care home, we were advised not to do any digital rectal examination. So that might be according to the law."* [Group Interview-2: Staff]	1. Clinician expertise (resource) 2. Care staff feel confident to accept delegated role (reasoning)	**Appropriate assessment that leads to treatment of bowel symptoms** CMO = Appropriate assessment leading to treatment (O) may be triggered by a clinician taking lead in assessment (e.g., digital rectal examination) (M) because care staff do not have the permission or expertise to carry out invasive examinations (C) of residents.

	NEW INSIGHT	**Staff clinical judgement, combined with/supported/reinforced by clinician input and documentation (e.g., bowel charts, fluid charts, and food charts) that provides accurate resident specific information.** MP3: *"As carers we recognise the signs of constipation very easily in our unit. So, if you see somebody is more disorientated than usual, if there is no urine infection or chest infection it should be the bowel and like 60% of the time when you do a referral it's come out as they were just constipated."* [FGD]	1. Shared planning and decision making (resource) 2. Use of clinical judgement (e.g., use of bowel charts, experience, etc.)	**Earlier detection of bowel problems (e.g., constipation/faecal impaction)** CMO = Earlier detection of bowel problems among care home residents (O) may be achieved when there is shared decision-making process between care staff and clinicians (M), because in most cases care staff make referrals (C) based on their clinical judgements (M).

Key: PT = Programme Theory; FGD = Focus Group Discussion; MP = Male Participant; FP = Female Participant; CMO = Context-Mechanism-Outcome

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT2: Ongoing teaching, review, and feedback for care home staff on how to reduce and managed FI	EVIDENCE	**Bowel care training to improve staff confidence in performing bowel care.** **HCA:** *"We don't get specific training in bowel care. We do have training in other care areas that overlaps bowel care, but it will be useful to have a mandatory bowel care training as part of staff inducting since the majority of our job as Care Assistant is taking residents to toilet and helping them with hygiene needs…"* [Individual Interview] **RN:** *"We are expecting a continence nurse to come and give training to all the staff and then from there we would be having a meeting for all the leads to ensure that we are providing good equipment and then we, because those unit where they've got a resident with a little cognition then they can do toileting regime, taking them to the toilet, see if it can improve their incontinence like not using and sitting on the wet pad. But that would be after training with the incontinence nurse."* [Individual interview] **Respondent-2**: *"I think it is more about educating people. You train them, you educate them. To improve the care. It is all about communication and educating people."* [Group Interview-2: Staff]	1. Staff acquire knowledge from training (resource) 2. Triggers staff to recognise and interpret residents' continence needs (reasoning)	**Improved continence care** CMO = Improved continence care (O) may be achieved when care staff trained, educated, and/or given feedback (C) because knowledge gained from training/feedback (C) may trigger how care staff recognise and interpret residents' care needs.
		Need to provide staff support/feedback **RN**: *"It will be a good thing if we had something you feedback. It's not going to be on our level or carers level how to prevent incontinence."* [Individual Interview]	1. Feedback triggers changes in how staff prioritise residents' continence needs (reasoning)	

	NEW INSIGHT	Although staff seem to subscribe to wanting some sort of training in bowel care, the content of such training remains unknown. **Respondent-1**: *"I am not really sure what we will need for staff to be trained to do. Basically, how important bowel care is and how important it will improve skin conditions of our residents. And how important reporting and communicating loose bowel can be."* [Group Interview-2: Staff]		

Key: PT = Programme Theory; HCA = Healthcare Assistant; RN = Registered Nurse; CMO = Context-Mechanism-Outcome

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT3: Addressing on the cause and prevention of constipation	EVIDENCE	**A common understanding/vocabulary that can describe different kinds of stool using bowel charts (Bristol stool charts).** **MP2**: *"On my unit all residents are on bowel chart which means end of the shift even those who are independent we go and ask them, did you open bowel?"* [FGD] **FP4**: *"I do the repeat prescriptions if I notice, for example, that someone has been omitting their laxatives for 2 or 3 weeks due to loose bowels sometimes that does happen and I do flag up saying I think probably this needs to be reviewed."* [FGD]	1. A system to recognise bowel problems (resource) 2. Prompts staff to review medication management, fluid and nutrition intake (reasoning)	**Reduction of residents' discomfort due to constipation and episodes of FI** CMO = Reduction of residents' discomfort due to constipation and FI episodes (O) may result when there is recognised system which all care staff understand (e.g., use of bowel charts) (C), because such charts prompt the staff to review residents' medication management or nutrition and fluid intakes (M).
		Focus on recognition and treatment and/or management of constipation. **FP5**: *"There are a number of factors we would consider if a person is constipated, one of them being if they are already on laxatives and if they are at risk of malnutrition and dehydration. … And one of the things we look at is bowel movement and when their last bowel movement was and if it's affecting appetite overall ".* [FGD]. **Respondent-1**: *"Let's say for example, if a resident is mobile, we encourage mobility. If not, then we go by diet like give fibres, fruits, prunes, and porridge. Then we keep hydrating them as they drink lot of fluid. And if that doesn't help, we just have to manage with medication."* [Group Interview-2: Staff]	1. Reliance on expertise or clinical judgement (resource/reasoning) 2. Familiarity with resident (resource/reasoning)	

	NEW INSIGHT	Problem with dietary modification within the care home setting. FP5: *"if you have someone who is not eating and drinking very well it will be difficult particularly if all they want to have is say puddings. So, their main diet will be chocolate mousse and desert at lunch and dinner, it will be very difficult to get fibre in that way and if they are on a texture modified diet as well."* [FGD] Sometimes surgery, instead of conservative management, may be required. FP: *"There's a resident on my unit who was on regular enemas where sometimes he has to be admitted to the hospital for that to be sorted out. Now it's good news, he's had an operation, and everything is opening regular with just laxative he doesn't a lot of...Yes, regarding his constipation, I can't remember what the operation is, but he's been very stable with regards to his bowel movement."* [FGD]		

Key: PT = Programme Theory; FGD = Focus Group Discussion; MP = Male Participant; FP = Female Participant; CMO = Context-Mechanism-Outcome

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT4: Interventions that reflect the degree of cognitive and physical capacity of the resident	EVIDENCE	History of residents' bowel patterns and their signals for needing help with toileting. **FP9:** *"We do, so we always assess the residents when they first come in or their functional ability changes when we've reviewed them, if there's no change to their baseline and we will put some adaptations in place in their environment, in their toilet, and making sure the rails are in place, make sure they're safe and also raise the toilet to an appropriate height so they're actually off easily and to give them as good of a posture as possible so they can actually open their bowels much more easily."* [FGD] **MP1**: *"When the resident is coming in [the care home] we have the incontinent assessment and then we review it and if something changes while the person is here."* [FGD] **FP3:** *"when a resident comes you do a care plan, you have to do the elimination care plan, then the incontinence assessment and you can see those challenges and if they have a challenge then you have to do the referral, then you have to refer them if they are incontinent how are you going to manage it."* [FGD] Incorporating person-centred care approach **MP3:** *"We have a gentleman on my unit now and he's clockwork, so he's up at 7.30am, he has his breakfast between 8am, about 8.55am he gets himself back to his bedroom and then he's on the toilet from about 9.05am to 9.25am every morning. So, staff know that now, we've learnt that now, so even though he's immobile and he needs full support with toileting and whatnot and aids and whatnot. I've never known him be incontinent because staff are aware."* [FGD]	1. Staff conceptualise continence care as unique to individual resident (reasoning) 2. Common understanding of individual resident care needs (resource/reasoning)	Minimisation of distress and promotion of comfort among residents CMO = When staff document accurate history of a resident's normal bowel patterns and signals for needing toilet assistance (C), it enables staff to conceptualise bowel care as unique to individual resident (M); this ultimately promotes minimisation of distress among residents (O), fosters their comfort (O), and potentially result to more dependent continence rather than FI (O).

	NEW INSIGHT	Even if staff take detailed history when a resident first come into the care home and staff carry out detailed assessment resulting to individualised person-care, implementing care plans require adequate staffing. HCA: *“Maybe just to get more staff on the ward you know…because some of these residents are hard to look after because of their dementia.”* [Individual Interview] FP2: *"I mean the carers are brilliant but again they are short staffed on a fairly regular basis.”* [Group Interview-2: Relative 2] HCA: *“Maybe enough staffing because many days we have agency staff here. While that is good because they can help with some problems, it can be difficult for the regular staff because show them how to do things and that can be hard. So, we need many staff maybe that way we can do better in bowel care”* [Individual Interview]		

Key: PT = Programme Theory; FGD = Focus Group Discussion; MP = Male Participant; FP = Female Participant; HCA = Healthcare Assistant; CMO = Context-Mechanism-Outcome

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT5: A common understanding of the potential for recovery, reduction, and management of FI	EVIDENCE	**Therapeutic nihilism (believe that nothing can be done and therefore nothing should be attempted).** **RN:** *"[FI] is age related and then with dementia as we know dementia is a progressive disease once it's affect that part of the brain I don't think the person would be cured and then they came back continent and then able to talk and use the toilet by themselves. I think it is difficult for elderly living in the nursing home with dementia and with being incontinent."* [Individual Interview] **HCA:** *"do you think there is anything we can do to make bowel care better? I really don't think so because when someone has dementia it is like uphill battle. You struggle to know if the person is in pain, needs help to go to the toilet, and why not."* [Individual Interview] **Respondent-1:** *"Are you sure we can? I don't think so, because dementia is a progressive condition. What happens is that at first, they have one form of incontinence. As they deteriorate, they become doubly incontinent. So, for me personally, I don't think there will be any improvement with their bowels or incontinence."* [Group Interview-2: Staff]	1. Nihilistic belief regarding FI leads to inaction (reasoning) 2. Lack of motivation among care staff (reasoning)	FI normalised as inevitable CMO = When care staff do not believe that anything can be done to reduce FI episodes (C), this preconceived notion demotivates them to think about any management strategies (M) and as the result, FI is normalised (O).
		Belief that FI can be ameliorated by intervention. **FP1:** *"Well you can again with diet and medication review, I don't know about in all cases but some cases."* [FGD]	Belief that FI can be managed motivates care staff	Promotes continence and FI management CMO = When care staff believe that FI can be ameliorated by intervention (C), this encourages/motivates them to pursue management strategies (M), which could potentially promote continence.

	NEW INSIGHT	There is dissonance between what the care staff expressed was possible and what they believed about FI management in older people with dementia in care homes. *“**Yes, we can** [reduce episodes of FI in residents with dementia]. It is **a tricky question to say how**.”* [Group Interview 2: Staff Respondent 1]		

Key: PT = Programme Theory; FGD = Focus Group Discussion; FP = Female Participant; HCA = Healthcare Assistant; RN = Registered Nurse; CMO = Context-Mechanism-Outcome

Theoretical assumptions		Contexts that trigger actions and responses	Mechanisms (reasoning/resource)	Outcomes (intended/unintended)
PT6: When care of people living with dementia and FI is integral to the work patterns of the care home and its staff	EVIDENCE	**Everyday work pattern and environment of the care home.** **FP3:** *"Then it's a routine as well like after breakfast they attend activities, so between 11.00am to 11.30am just to use the towel just to see that they are dried; wash their hands and then get them to the tables. Then in the afternoon it's after teatime or prior teatime, and then after supper."* [FGD] **FP7:** *"so if I'm working on each wing, I need to ensure that the residents are being assisted to use [toilet] whether they are ready or not ready just to try to prevent them from having an accident because sometimes they feel bad as well when they are incontinent."* [FGD]	1. Triggers staff to do the right thing (reasoning) 2. May lead to risk aversion (reasoning)	**Reduction in FI episodes** CMO = Episodes of FI can potentially be reduced (O) if care staff understand how dementia impacts continence care (C), and the staff incorporates person-centred care into everyday routines of the care home (C). The mechanisms are that staff will understand why individual residents behave in certain ways (M), thus enabling the staff to do the right thing (e.g., provide timely toileting assistance, change of incontinence pads, etc.) (M).
		Understanding how dementia impacts continence. **FP3:** *"In advanced dementia Unit, we did have a resident who used to do faecal smearing. So that person used to wake at 5am and open her bowel and she was on ferrous sulphate so very blackish bowel. And if you didn't get to her at the right time and support her, she could paint the whole bathroom wall. She would paint it in multiples of colours"* [FGD] **FP1:** *"She's very independent, she can go to the toilet and then she will forget it the next moment. Sometimes there are smears in the toilet that can give you a hint."* [FGD]	1. Staff understand why individual behave in certain ways (reasoning/resource) 2. Triggers pre-emptive support for the resident (e.g., change of incontinent pad) (resource/reasoning)	

	NEW INSIGHT	Challenges to incorporating person-centred care with continence in residents with dementia. MP1: *"the hardest part is when the residents are fighting back during personal care especially when they are big and strong. So there are staff that they are complaining that they are not feeling comfortable and sometimes we are not restricting anyone here but you have to be extra careful with these ones to support them even more. But you don't know that if you put more staff let's say to go to the toilet or with this resident if it will make it worse or if it will be."* [FGD] HCA: *"You know, sometimes a resident may be calm to let one person help him. Other times that same person may not want anyone to come close."* [Individual Interview] FI knowledge and appropriate staffing levels. FP2: *"I mean the carers are brilliant but again they are short staffed on a fairly regular basis."* [Group Interview-1: Relatives] HCA: *"Maybe just to get more staff on the ward you know…because some of these residents are hard to look after because of their dementia."* [Individual Interview]		

KEY: PT = Programme theory; RN = Registered Nurse; HCA = Healthcare Assistant; MP = Male participant; FP = Female participant; CMO = Context-Mechanism-Outcome

6.9.1 Do the programme theories proposed by the FINCH Study resonate with care home stakeholders?

The findings from the stakeholders' consultation to determine how the theory areas resonate with stakeholders are presented in Table 6.4 above, with detailed analysis below. Those theories that had the most resonance with the stakeholders are acknowledged and will be used to help to develop a bowel care intervention for residents in care homes.

6.9.2 Programme Theory 1: Clinical-led assessment and ongoing support

The assumption of this first programme theory is that the involvement of clinicians such as the Clinical Nurse Specialists (CNS), visiting District Nurses (DNs), or General Practitioners (GPs) is key because care home staff do not have the authority or expertise (C) to be able to complete an assessment, particularly digital rectal examination, diagnosis of diarrhoea or a drug review (Goodman et al. 2017). According to this theory, when such clinicians take a lead, care staff will become confident (M) to accept (M) the delegated responsibility of assessment and management of FI, and the shared communication and review of residents increases staff awareness and involvement in continence care (M). Care home staff may then observe and document changes in the resident and this is fed back into the assessment/review process, and this reinforces (M) practices that support effective continence care (O) (Goodman et al. 2017).

How this programme theory resonates with the stakeholders in this research study is presented in Box 2.

Box 2: Programme theory 1 (PT1)
Clinician-led assessment and ongoing support and review informed using jointly agreed approaches to the promotion of continence and alternatives to the use of pads will achieve observable improvements in continence and resident well-being.

On-site GP and availability of Advanced Nurse Practitioner (ANP) for advice, review, and/or referral for immediate clinical input.

Quote-1: *"So, each unit has its own GP, so they get a visit once a week from their GP. So, any routine reviews would be referred … if I notice, for example, that someone has been omitting their laxatives for 2 or 3 weeks due to loose bowels, sometimes that does happen, I do flag up saying I think probably this needs to be reviewed."* [FGD- FP4]

Quote-2: "*We have the incontinence lead now in each unit that we will be having a meeting…. For residents who are experiencing faecal incontinence, with an underlying cognitive impairment, we'd not be able to stop that due to their conditions …"* [FGD- MP2]

Quote-3: "*we can always refer to the GP or to our ANP. They will come to review and then we continue monitoring how the person goes.*" [FGD- MP1]

Quote-4: *"We are not…well I am trained to do it [rectal examination], but we are not allowed to do it here. We have the advanced nurse practitioners who are allowed to do those things. …when I started working here even when I was working in another care home, we were advised not to do any digital rectal examination. So that might be according to the law."* [Group Interview-2: Staff-: Respondent-2]

CMO = Earlier detection of bowel problems among care home residents (O) can be achieved by the clinician (C) when the care home staff access to engage with and involve the clinician (M).

CMO = Appropriate assessment leading to treatment (O) may be triggered by a clinician taking lead in assessment (e.g., digital rectal examination) (M) because care staff do not have the permission or expertise to carry out invasive examinations (C) of residents.

PT1 = programme theory 1; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FGD = focus group discussion; Quote = verbatim quotes form an f individual participant

As can be seen from Box 2, ***Quotes 1 and 3*** demonstrate staff access to clinician such as a General Practitioner (GP) or Advanced Nurse Practitioner (ANP) to review residents' medication management. They also demonstrate that care staff feel supported when they can work with a clinician and can make referrals in areas that fall outside their expertise. The regular, expected access to clinicians, and the feelings among the care staff to refer a resident when something has changed (i.e., that their observation will be welcomed and acted upon by the GP or ANP) are important mechanisms that can lead to earlier detection of bowel problems and appropriate assessment of residents. The assumption that they could access a clinician's advice and that conversations were characterised as discussions was a context that cannot be assumed for all long-term care settings.

Box 2, **Quote-*2*** highlights that leadership in care components (i.e., continence care) can potentially shape the thinking of the care staff. The staff member seems dismissive about potential intervention for residents experiencing FI and having dementia, which could be due to lack of education or appropriate training, as addressed under Programme Theory 2 below. Notwithstanding, having a continence lead in each unit could potentially contribute to a team resource (e.g., the team could build their expertise about managing continence generally and the continence of specific residents) by pooling knowledge and building pattern recognition in bowel care. This could potentially help the care home staff to have a consistent approach to managing FI and to deal with situations when they feel they cannot prevent incontinence.

Box 2, ***Quote-4*** suggests that care home staff do not generally have the mandate to carry out invasive assessments, probably due to safeguarding issues. It further confirms the need for clinician involvement in assessing residents because such duties do not fall within the clinical expertise of the care staff.

The data supports PT1 and could be interpreted in two ways: 1) Earlier detection of bowel problems among care home residents (O) can be achieved by the clinician (e.g., ANP or GP) (C) when the care home staff have access to engage with and involve the clinician (M). 2) Appropriate assessment leading to treatment (O) may be triggered by a clinician taking the lead in assessment (e.g., digital rectal examination) (M) because care staff do not have the permission or expertise to carry out invasive examinations (C) of residents. There is also evidence to suggest that earlier detection of bowel problems among care home residents (O) may be achieved when there is a shared decision-making process between care staff and clinicians (M), because in most cases care staff make referrals (C) based on their clinical judgements (M) and lack of expertise (M):

> *"As carers **we recognise the signs of constipation very easily** in our unit. So**, if you see somebody is more disorientated than usual, if there is no urine infection or chest infection it should be the bowel and like 60% of the time when you do a referral it's come out as they were just constipated**."* [FGD-MP3]

The following extract, from observation field notes, triggered a line of thinking about the presence of a clinician in continence care of older people living in care homes, which provides additional insight about PT1:

> *"In my role I allocate staff depending on how well they know the residents. So, when they [care staff] are working and see that the resident stool is hard, or let say it's diarrhoea, they report it to me, or the Nurse in Charge. But the thing is* ***we can't really do anything about it right anyway until the GP comes and review because we are not trained to do digital rectal examination.*** *And sometime this can take few days before the review can happen."* [Conversation with a senior care assistant relating to clinical lead support]

The field notes narrative and Box 2, **Quote-4** suggest that it is not just about dialogue and support with clinicians to increase staff confidence, but there are aspects of care assessments linked to regulatory procedures in terms of who can do what.

One would wonder why the care staff rely solely on the GP/ANP and not also rely on the registered nurses (RNs) who work with the residents and could potentially perform digital rectal examination. An interview with a former geriatrician (a care home commissioner at the study site) revealed that while she was in practice, she routinely carried out digital examinations of all residents who showed signs of constipation, and those that presented with loose stool. According to her, a resident with only urinary incontinence (UI) was usually not examined, but those presenting UI and FI were digitally examined to rule out faecal impaction. She explained that there were other ways to detect constipation, such as abdominal x-rays, but such diagnostics required hospital attendance or admission of a resident. A male participant at the FGD confirmed that residents are sometimes sent to hospitals due to problems with constipation:

> "*We had a lady, and* ***she didn't open bowel for a few days, we sent her to the hospital****, she came back as palliative and after a few days she passed away."* [FGD-MP1]

Returning to the interview with the former geriatrician, she recounted that even in hospitals doctors usually failed to diagnose constipation or faecal impaction. The lack of mandate for care home registered nurses to perform digital rectal examination combined with difficulty of doctors in hospitals to detect constipation or faecal impaction potentially leads to late diagnoses as acknowledged by a resident's relative:

> *"I mean he did have fairly regular habits at one point, but he also has a problem of having to have medication now because* ***he wasn't able to go and ended up in***

> ***hospital. They thought he'd got a tumour but it wasn't, he was actually constipated*** *and the whole of his stomach had blown up and he had a temperature."* [Group Interview-1: Relative 2]

On the question of why registered nurses could not perform rectal examination, the former geriatrician explained that in one care home where she worked, she became concerned about how care staff performed manual evacuation. In that care home, a GP had instructed the care staff to carry out routine manual evacuation on residents, which according to her, equated to a rape. Although digital rectal examination and manual evacuation are different, both aspects inherently involve invasive procedures (e.g., inserting finger into the patient's rectum). It potentially confirms how continence care is linked with intimacy, and why staff feel exposed to misunderstanding and misinterpretation of their actions that could be interpreted as assault.

Three RNs at the current study site were asked if they could perform rectal examination and the three RNs said that they could not carry out digital examination because they had not been trained to do so. This further demonstrates a gap in current practice and necessitates training to enable RNs (and possibly senior Care Assistants) to provide a digital rectal examination. This overlaps PT2 which concentrates on staff training (see below).

6.9.3 Programme Theory 2: Ongoing teaching and feedback for staff

This programme theory expresses that giving staff access to the appropriate training, education and facilitation will result in a change in practice (C). The mechanisms are that knowledge, feedback, and review (C) trigger changes in how staff recognise and interpret (M) residents' continence needs (and discuss with visiting clinicians as discussed in PT1), their confidence (M) and how they work; the assumption is that this will lead to improved continence care (O) (Goodman et al. 2017). This theory is important to consider because so many care home interventions employ a training/education/facilitation approach. The evidence in relation to this theory is summarised in Box 3 below for easier reference.

Box 3: Programme theory 2 (PT2)
Ongoing teaching and feedback for staff that involves care home staff in planning, action, review and will achieve positive continence-related outcomes.

Quote-1: *"We don't get specific training in bowel care. We do have training in other care areas that overlaps bowel care, but it will be useful to have a mandatory bowel care training as part of staff inducting since the majority of our job as Care Assistant is taking residents to toilet and helping them with hygiene needs…"* [Individual Interview-HCA]

Quote-2: : *"We are expecting a continence nurse to come and give training to all the staff and then from there we would be having a meeting for all the leads to ensure that we are providing good equipment and then we, because those unit where they've got a resident with a little cognition then they can do toileting regime, taking them to the toilet, see if it can improve their incontinence like not using and sitting on the wet pad. But that would be after training with the incontinence nurse."* [Individual interview-RN]

Quote-3: *"I think it is more about educating people. You train them, you educate them. To improve the care. It is all about communication and educating people."* [Group Interview-2: Staff-Respondent-2]

Quote-4: *"It will be a good thing if we had something you feedback. It's not going to be on our level or carers level how to prevent incontinence."* [Individual Interview-RN]

CMO = Improved continence care (O) may be achieved when care staff trained, educated, and/or given feedback (C) because knowledge gained from training/feedback (C) may trigger how care staff recognise and interpret residents' care needs.

PT2 = programme theory 2; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FGD = focus group discussion; Quote = expressions of individual participant

The data in Box 3 suggests that care staff at the study site do not currently receive specific training in bowel care (**Quote-1**). The lack of specific bowel care training such as training in other care components (e.g., nutrition and hydration, food hygiene, etc.) was also expressed by another healthcare assistant:

> *"I have had bowel care training in the past. I was shown a video demonstrating how to clean the bum of a doll. But that was long time ago now.* ***I think most people just assume that everybody knows how to clean bum****…. If we have new staff, we can shadow them for few weeks just to make them get used to doing the job. Apart from that* ***we don't really attend bum cleaning training****"* [Individual interview-HCA]

Notwithstanding this staff seems to acknowledge nonexistent bowel care training in the care home, the statement could also be interpreted as restricting bowel care to hygiene needs after an incontinence episode. The finding further demonstrates the low value placed on continence training, vis-à-vis the very narrow understanding of what is required to help someone become continent. While there is evidence to suggest the need for training and education in continence care (Box 3, **Quotes 1** and **2**), the care staff do not seem unanimous on the need for such education and training as noted during a field observation:

> *"Well…actually **it is just common sense**. Of course, when we first join the team they make us to know the resident care plan. **Over time we get used to the resident and we can tell sometime if the person needs toileting**. **The continence care training we receive is usually when we are having different types of training like fall or talking about skin integrity. We don't have specific continence care. Maybe that could help** to know more you know."* [HCA]

While the mention of "*it's just common sense*" by the care assistant could be viewed as not valuing training or education in continence care, such common sense arguably develops over time. Acknowledging this 'common sense' as valuable skills may be helpful in giving confidence to care staff. PT1 suggests that care staff are reassured by visiting clinicians, but carers are likely to be providing crucial assessment information and insights which are equally important. An intervention that incorporates how this 'common sense' can be used to carry out continence care would be useful.

While there is currently no specific bowel training at the study site, the findings from the realist evaluation (stakeholders' engagement) suggest that improved continence care (O) may be achieved when care staff are trained, educated, and/or given feedback (C) because knowledge gained from training/feedback (C) may trigger how care staff recognise and interpret residents' care needs (M).

However, what support exactly is required remains unclear. This is a new insight into PT2 because the existing theory attaches importance to staff training and education without specifying what sort of training or educational need would be required by the care staff. This new insight suggests that a bowel care training should more likely address the causes of bowel problems and the impact of incontinence.

> *"I am not really sure what we will need for staff to be trained to do. Basically, **how important bowel care is** and **how important it will improve skin conditions** of our residents. And **how important reporting and communicating loose bowel can be**. I don't think there will be any special education on how you do continence care because all of us here should know how we go about doing it. I think **it should cover the pros and cons about giving frequent continence care**."* [Group Interview-2: Staff – Respondent-1]

This finding further raises important questions about why skin integrity should be prioritised, possibly because it is one of the indicators of quality care by regulatory bodies such as Care Quality Commission in England, Healthcare Inspectorate Wales, or the Care Inspectorate in Scotland (whereas continence care is not – even though it should be).

6.9.4 Programme Theory 3: Dealing with constipation in older people with dementia

This programme theory posits that a focus on the recognition, treatment and management of constipation (C) will prompt (M) staff to review residents' medication management, fluid and nutrition intake, as well as bowel function and residents' activities such as exercise (C) and communication strategies that encourage (M) the resident to ask for staff assistance (or be willing to engage in regular toileting) may lead to appropriate containment and reduction of FI and resident discomfort and pain (O) (Goodman et al. 2017). Box 4 contains the evidence from the stakeholders' consultation during this phase of the research study.

Box 4: Programme theory 3 (PT3)
Dealing properly with constipation in older people with dementia in care homes will ameliorate a significant proportion of faecal incontinence as it is laxative induced or overflow faecal incontinence due to constipation and impaction.

Quote-1: *"On my unit all residents are on bowel chart which means end of the shift even those who are independent we go and ask them; did you open bowel?"* [FGD-MP2]

Quote-2: "*In the nursing home constipation for the elderly is quite high because with dementia they tend to forget things they are supposed to do. They're not drinking much unless you push the fluid. They need to eat healthy diet, balanced diet…more fruit to help go to the toilet*" [Individual Interview-RN].

Quote-3: *"I do the repeat prescriptions if I notice, for example, that someone has been omitting their laxatives for 2 or 3 weeks due to loose bowels sometimes that does happen and I do flag up saying I think probably this needs to be reviewed."* [FGD-FP4]

Quote-4: *"Let's say for example, if a resident is mobile, we encourage mobility. If not, then we go by diet like give fibres, fruits, prunes, and porridge. Then we keep hydrating them as they drink lot of fluid. And if that doesn't help, we just have to manage with medication."* [Group Interview-2: Staff – Respondent 2]

CMO = Reduction of residents' discomfort due to constipation and FI episodes (O) may result when there is recognised system which all care staff understand (e.g., use of bowel charts) (C), because such charts prompt the staff to review residents' medication management or nutrition and fluid intakes (M).

PT3 = programme theory 3; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FGD = focus group discussion; Quote = expressions of individual participant

The data provided in Box 4 (above) supports the programme theory that reduction in residents' discomfort due to constipation and FI episodes (O) may result when there is recognised system which all care staff understand (e.g., use of bowel charts) (C), because such charts prompt the staff to review residents' medication management or nutrition and fluid intakes (M).

The staff in the care home acknowledged that managing constipation, especially in residents with underlying dementia was challenging (Box 4, **Quote-2**). Monitoring residents' bowel movements using bowel charts which distinguishes stool consistency such as the Bristol Stool chart is idea for identifying residents at risk of constipation (Box 4, **Quote-1**). The use of such a stool chart could serve as a benchmark for the care home staff to omit laxatives for certain residents who may routinely be receiving laxative medication as a prophylaxis to prevent constipation (Box 4, **Quote-3**). The need for care staff to manage constipation conservatively (e.g., through exercise and/or dietary modification) in an individual resident is highlighted (Box 4, **Quote-4**). Each of these factors need to be considered when developing an intervention to prevent or manage constipation in older people living in care homes, especially for those with underlying dementia.

Having dementia has a profound effect (e.g., creates distress and anxiety) on the individual's ability to remember to use a toilet when there is a need to do so, to find a toilet facility, and/or to undress even when the person is in the toilet:

> *"**We have one lady** who is always complaining of constipation. Hers is mainly **with the short-term memory loss so can open her bowel now and in two seconds she will forget it. And her anxiety and her distress everything is revolving around this constipation**."* [FGD-FP1]

Finding from the stakeholders' engagement suggests that care staff need to look for cues in residents with dementia such as symptoms of pain to determine whether a resident need toilet assistance or help with constipation:

> *"I think **it's the memory** especially on our unit. **Cognition. Some of them just don't have the control**. Sometimes some underlying illnesses **they feel like going, going, they have pain or it's not coming**, like they just have the urge to go, that might be an illness or something but mostly it's the cognition."* [FGD-FP7]

Staff need to be aware of overuse of laxatives, which in most cases can result to watery or loose stool with FI consequences.

> *"We still have a resident that **needs daily enemas and even if he's passing watery stool,** we have to wait a bit to calm down and then to give the enema because of the instructions…otherwise he might become constipated."* [FGD-MP1]

As well as the exercise and dietary interventions, ensuring that care staff encourage residents to drink fluid was advised by the stakeholders. The two relatives interviewed in this study seem to agree with the need to keep residents hydrated and to provide residents with a healthy balanced diet to improve their gut motility. One of the relatives also suggested practical solutions that staff could take to prevent constipation in the first place.

> "*Staff have to* ***be more aware*** *and up to speed to* ***keep their eyes on each patient to check that they are having enough to drink****. It's all very well giving medication but unless they're having water as such or something to drink fairly regularly. Medication is fine but they still need liquid and good food."* [Group Interview-1: Relative 1]

In addition to staff looking out for residents with dementia who may be at risk of constipation, other factors such as immobility (e.g., wheelchair users who are dependent on care staff for transfer) should be prioritised by care staff.

> *"I think* ***the major problem*** *[concerning constipation]* ***is the fact that people are immobile and*** *that's where they* ***are not independent****; for example, they are not having sufficient exercise***. If people can walk around, they can probably sort themselves out and have a bowel movement*** *but if you are stuck in a wheelchair then it needs more attention to check on the patient…perhaps more."* [Group Interview-2: Relative 2]

A new insight in this programme theory is that dietary modification for some care home residents is not always possible due to other comorbidities of the individual resident.

> *"If* ***you have someone who is not eating and drinking very well it will be difficult particularly if all they want to have is, say, puddings****. So, their main diet will be chocolate mousse and desert at lunch and dinner,* ***it will be very difficult to get fibre in that way and if they are on a texture modified diet*** *as well."* [FGD-FP5]

Another new insight in PT3 is that, although constipation can be conservatively managed (e.g., through exercise and dietary modification), there may be instances that only surgery will be an option.

> *"There's* ***a resident*** *on my unit who* ***was on regular enemas where sometimes he has to be admitted to the hospital for that to be sorted out****. Now it's good news,* ***he's had an operation, and everything is opening regular*** *with just laxative he doesn't a lot of...Yes, regarding his constipation, I can't remember what the operation is, but he's been very stable with regards to his bowel movement"* [FGD-FP]

From observations, the study site seemed to have a routine way of serving meals to the residents. Although there was a menu for residents to choose from, the fact that many residents were unable to choose food options due to underlying dementia meant that food and snack choices were left with the care staff. The consequence of the care staff choosing for the resident was that almost every resident seemed to have the same type of meal, except for texture because some residents had problems with swallowing. The existence of individualised exercise was also lacking. After lunch, sometimes the activities coordinator came in the lunchroom and engaged the residents in group activities such as singing. The activities were not individualised. Notwithstanding, at these activities, the care staff seemed to understand how to encourage each resident to participate, taking the residents' cognition and physical ability into account.

Therefore, the alternative explanation for PT3 may be stated as: 1) Earlier detection and/or prevention of bowel problems such as constipation may result from improved care staff confidence level when they are supported by clinicians' input (PT1) and the care staff are able to use a systematic approach to consult documentation (e.g., bowel charts) to confirm residents' bowel movement frequency, and there are other ways (e.g., cues from residents' body language) for the staff to notice and act when a resident needs toilet assistance or is already experiencing constipation. 2) Adequate hydration, which has beneficial effect of preventing constipation, may suffice when staff recognise and provide regular fluid to residents, provided that accurate use of fluid charts is in place. 3) Constipation in older people may improve when care staff provide regular/daily exercise to residents at risk of the condition.

6.9.5 *Programme Theory 4: Taking account of the history, preferences and wishes of a person*

This area encapsulates the person-centred care (PCC) approach to care. It assumes that if the resident, their history, their normal bowel patterns and their signals for needing the toilet are known (C) and staff are able to document and review in collaboration with a clinician assessment and family input (C) this means staff conceptualise continence care as unique to the individual resident (M) with the result that there is more dependent continence rather than FI (and UI) as well as outcomes that are consistent with the minimisation of distress and promotion of comfort (O) (Goodman et al. 2017).

Box 5: Programme theory 4 (PT4)
Interventions that take account of the history, preferences and wishes of the person together with acknowledgement of the degree of cognitive and physical capacity of the resident (individualised care) will reduce faecal incontinence.

Quote-1: "*We do, so we always assess the residents when they first come in or their functional ability changes when we've reviewed them, if there's no change to their baseline and we will put some adaptations in place in their environment, in their toilet, and making sure the rails are in place, make sure they're safe and also raise the toilet to an appropriate height so they're actually off easily and to give them as good of a posture as possible so they can actually open their bowels much more easily.*" [FGD-FP9]

Quote-2: *"…we don't treat them in general, although they have got dementia, but we treat them [as] individual"* [Individual Interview-RN]

Quote-3: *"when a resident comes you do a care plan, you have to do the elimination care plan, then the incontinence assessment and you can see those challenges and if they have a challenge then you have to do the referral, then you have to refer them…if they are incontinent how are you going to manage it."* [FGD-FP3]

Quote-4: "*We have a gentleman on my unit now and he's clockwork, so he's up at 7.30am, he has his breakfast between 8am, about 8.55am he gets himself back to his bedroom and then he's on the toilet from about 9.05am to 9.25am every morning. So, staff know that now, we've learnt that now, so even though he's immobile and he needs full support with toileting and whatnot and aids and whatnot. I've never known him be incontinent because staff are aware.*" [FGD-MP3]

CMO = When staff document accurate history of a resident's normal bowel patterns and signals for needing toilet assistance (C), it enables staff to conceptualise bowel care as unique to individual resident (M); this ultimately promotes minimisation of distress among residents (O), fosters their comfort (O), and potentially result to more dependent continence rather than FI (O).

PT4 = programme theory 4; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FGD = focus group discussion; Quote = expressions of individual participant

The data in Box 5 (above) supports PT4. The evidence demonstrates that when care staff document accurate history of a resident's normal bowel patterns and signals for needing toilet assistance (C), this may enable the care staff to conceptualise bowel care as being unique to individual resident (M) and this can ultimately promote minimisation of distress among residents (O), fosters their comfort (O), and potentially result to more dependent continence rather than FI among the residents (O).

During the stakeholders' engagement, the stakeholders acknowledged the importance of holistic assessment and the need to incorporate person-centred care (Box 5). As well as holistic assessment, the stakeholders gave evidence of how dementia impacts continence:

> *"…**we've got a resident who smears faeces** which can maybe be due to constipation. **Because of dementia they are feel like they have got something** and then they start digging in themselves."* [Individual Interview-RN]
>
> *"Sometimes you know **some of these residents have dementia** and why not. So, if, for example, the **resident put his hands down there and begin to dig the poop out**, it may be that the person is constipated… **For bowel care, it helps if the resident is able to walk to the toilet and the resident is compliant.** You know some of **these residents, even when they walk to the toilet they just stand there**, and you can't force them to go to toilet. So, dementia has huge impact on continence."* [Individual Interview-HCA]
>
> *"Say for example, **when a resident with dementia needs to go to the toilet**, hmmm…if one is mobile, I've seen this one, **he keeps pacing around saying that he has to go somewhere but he can't say where**."* [Group Interview-2: Staff Respondent 1]

The stakeholders gave many examples of how they support residents with dementia, like the two staff members who are quoted below:

> *"**If she's got memory problem it means at times** when she opens [her bowel] **I have to come and give her personal care**."* [FGD-MP2]
>
> *"Well…sometimes you just have to guess **by offering a lot of support**. For example, **if the resident is walking towards the toilet**, you just go and ask **him if he needs to use the toilet. Or sometimes if the person is wearing incontinence pad and you see them pulling it off, it may be that they have already done it** and want to take it off, or maybe they want to use the toilet."* [Individual Interview-HCA]

Therefore, the need to incorporate person-centred care in everyday continence care based on individual's care plan (or in some cases, the care staff familiarity with the resident's routine) becomes paramount as were noted by these staff members:

> *"Yes…**we do know our residents**, and there are sometimes they will open their bowel. Like **some of them do it [open their bowels] first thing in the morning, some after breakfast, and some after lunch**. So if the person can sit on the toilet, **we will normally sit them on the toilet at the perfect time they normally open their bowel**. And if the person is not able to go the toilet, then of course, we will take them and change them [change incontinent pads]."* [Group Interview-2: Staff Respondent 2]
>
> *"**We have a resident living with dementia** what I have seen in my experience is **to give them time to sit on the toilet, depends on their routine**, like some go after breakfast, some early morning when you support them in the shower, they are on the dot incontinent. **So instead of letting them incontinent just let them sit on the toilet for a while.**"* [FGD-FP1]

However, another account from the data and from non-participant observation appears to challenge the evidence regarding person-centred care:

> *"**Then it's a routine** as well like **after breakfast they attend activities**, so **between 11.00am to 11.30am [we take them to toilet] just to see that they are dried**; wash their hands and then get them to the tables. **Then in the afternoon it's after teatime or prior teatime, and then after supper [we take them to toilet].**"* [FGD-FP3]

> *"It is difficult to engage with some of these people you know.* ***It is the memory problem****.* ***They don't understand even if you try to engage them****. So, the best thing is* ***to take them to toilet at certain time of the day*** *and hope that they will do it. But sometimes it is too late, so we have to clean them and change the pad you know."* [Care Assistant's account during observation]

The quotations from the last two staff members suggest the existence of routine care, as opposed to the person-centred care, in the care home. The two relatives interviewed in this study did not also seem to concur with the existence of person-centred care, particularly around how their relatives' physical ability to carry out certain tasks, or make informed choices were managed by the care staff:

> *"****Sometimes I've been here and they're dishing up tea and they've left a feeder mug half full of boiling tea expecting my husband to pick it up. He can't*** *because if he does, he'll spill it everywhere* ***because his hands now are losing their strength, and this is another problem with this horrible disease****."* [Group Interview-1: Relative 1]
>
> ***"My husband used to have dried fruit every day****, dried prunes, dates and things like that* ***which I think also helped****.* ***He hardly ever had to have special medication when he was at home to go to the loo****. It was only since he's been here which was mid-February that there have been these issues about bowel movements…well I know* ***the other day when I checked what my husband was having for breakfast there was no mention of prunes or prune juice****."* [Group Interview-1: Relative 2]

This account seems to be correct considering that all the residents have breakfast and lunch at the same time. Although when it comes to hygiene care (e.g., helping to wash residents), care staff generally leave some residents during morning hours until later in the day. And from observation, each resident also has a folder that contains the individual resident's care plan. But in practice, the care staff use more of their judgement (e.g., knowledge of the resident from experience) to provide care probably because most residents' care plan seemed very generic. This observation by the PhD candidate was even confirmed during one individual interviews with a staff member:

> *"****I know a lot of time people say care plan, care plan…but it doesn't work in majority of time.*** *You have to be a problem solver to think for them because they are confused and don't know what they are doing."* [Individual Interview – HCA]

The finding demonstrates that staff are aware of the importance of individualised care, but the individualised care is not always delivered. Additionally, the evidence raises an important point that the knowledge that care staff need as part of personal care work to improve continence is not the only requirement, but also how such knowledge is communicated and shared within the team. Clearly from the staff quoted above, other communication strategies such as the peer-to-peer learning described in PT1 (in addition to care plans) is needed.

From observations, the interplay between person-centred care and the staff workload always seemed to be a challenge because many regular staff were off sick due to Covid-19 (and this provides new insight into PT4). For example, a few of the residents often wished to go outside for walk but the staffing ratio could not accommodate this. During the time of this research study, agency staff were brought in to help alleviate the staff shortages. Generally, there was consistency in hiring the same agency staff, but sometimes other unfamiliar agency staff were seen working on the units in the care home. Perhaps in the absence of Covid-19 pandemic, the staffing issues would not have been a problem. But it must be acknowledged that this is a mere speculation.

While the FINCH theory advocates the involvement of family members in the care of a resident living with dementia in care homes, the evidence from this realist evaluation found that family involvement in the care can potentially become a challenge to the care home staff. These challenges form part of the new insight for PT4 and are summarised in Box 6.

Box 6: Perceived challenges from relatives of residents in care home

Quote-1: *"then for us the family don't accept it so the son what he does he comes by the lift and talks to you in the station, oh my mum is constipated blah blah so can you just give her something or the son will bring additional things you can get over the counter. So, the family will give her Senna and may unknowingly give her Senna as well, so again a double dose"* [FGD – FP]

Quote-2: *"We have a lady on a unit and her son is an herbalist, lives in America, posts packages of all herbal supplements, does not want his mother on any traditional medications. We did have to fight a massive battle and we got her on Docusate, but she has so many liquid herbal preparations that I have said to staff give the Docusate first because she doesn't like to drink all her meds"* [FGD – FP4]

Quote-3: *"when you have the families on top complaining and are on top of, behind your ear, by complaining. It's not the easiest. But OK we are not living in an ideal world, utopia, to have let's say 20 carers, 10 nurses and to have one to one, it's not possible"* [FGD – MP1]

Quote-4: *"So when the person comes and sometimes the room smells a bit because the previous night the person has does the same thing and you just call the carpet cleaners but because it's carpet and the smell stays so they will ask you why it smells. Then you explain that the same thing happened, and they will think oh but I thought that's why he or she came in the care home to manage it. But you are not managing it"* [FGD – FP7]

Key: FGD = Focus Group Discussion; MP = Male Participant; FP = Female Participant

6.9.6 Programme Theory 5: Establishing common understanding for managing FI

This area addresses and seeks to militate against beliefs of therapeutic nihilism (the belief that nothing can be done and therefore nothing should be attempted). In its place a belief and value system is advanced about the residents' potential to maintain or improve functional abilities even when the trajectory is one of deterioration (expressed in staff training, documentation, language of care and handover) (C), and that it is possible to ameliorate FI in residents living with dementia, will mean that staff will be willing to engage (M) and learn about what is causing the FI and attempt interventions (M) to promote continence and the management of FI are put in place (O) (Goodman et al., 2017).

Box 7: Programme theory 5 (PT5)
Establish a common understanding of the potential for recovery, reduction and management of faecal incontinence for people with dementia will result in attempts to reduce faecal incontinence.

Quote-1: *"[FI] is age related and then with dementia as we know dementia is a progressive disease once it affects that part of the brain, I don't think the person would be cured and then they came back continent and then able to use the toilet by themselves. I think it is difficult for elderly living in the nursing home with dementia and with being incontinent."* [Individual Interview-RN]

Quote-2: *"do you think there is anything we can do to make bowel care better? I really don't think so because when someone has dementia it is like uphill battle. You struggle to know if the person is in pain, needs help to go to the toilet, and why not."* [Individual Interview-HCA]

Quote-3: *"Are you sure we can? I don't think so because dementia is a progressive condition. What happens is that at first, they have one form of incontinence. As they deteriorate, they become doubly incontinent. So, for me personally, I don't think there will be any improvement with their bowels or incontinence."* [Group Interview-2: Staff Respondent 1]

Quote-4: *"Well you can again with diet and medication review, I don't know about in all cases but some cases."* [FGD-FP1]

CMO = When care staff do not believe that anything can be done to reduce FI episodes (C), this preconceived notion demotivates them to think about any management strategies (M) and as the result, FI is normalised (O).

CMO = When care staff believe that FI can be ameliorated by intervention (C), this encourages/motivates them to pursue management strategies (M), which could potentially promote continence.

PT5 = programme theory 5; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FP = female participant; FGD = focus group discussion; Quote = expressions of individual participant

The evidence shows that many of the staff at the care home did not believe in the potential to cure or reduce faecal incontinence in residents with dementia **(**Box 7, **Quotes 1** to **3** in

Box 6). Similar expression was also made by a health care assistant who provided toilet assistance to a resident living with dementia during one observation session. A resident was sat in the lounge with two other residents. As the PhD candidate approached the residents, he [the PhD candidate] smelt faeces. The PhD candidate then alerted the care staff to check the residents. It became apparent that the resident was incontinent of faeces. The resident was then provided toilet assistance by a care assistant. The care assistant was asked immediately assisting the resident "how can we prevent re-occurrence of such incident?" and she answered:

> "*It's more difficult when you're dealing with residents who haven't got capacity or who have got memory loss. Sometimes they keep saying toilet, toilet…and even if you take them, they will not do anything [open bowel or urinate].* ***There is really nothing we can do to stop them from being incontinent****. I don't know what the answer is for that*" [HCA].

This demonstrates, from a person-centred care perspective, that staff often have difficulty in interpreting certain behaviours from the residents. Over time this make staff to think that nothing can be done to improve incontinence. This nihilistic interpretation of care staff attitudes towards caring for a resident with dementia was also expressed by one of the two relatives interviewed:

> *"I think* ***because of*** *the mental capacity or* ***lack of mental capacity they're not necessarily sending the message to the brain*** *and so* ***wearing a pad I think they [care staff] actually encourage the person to if you like go when they want to if they are able to.*** *So,* ***they [the residents] can quite often be sitting in a wet pad and nobody is any there wiser*** *because there is no way that they know."* [Interview with a Relative]

Observation of care practice also suggests nihilism whereby care staff put incontinent pads on all the residents. While on one hand this may be interpreted as 'dignity care', it also provides a vehicle whereby care staff can attend to the resident when they feel (not when the resident feels) is right to provide incontinence care. The use of incontinent pads in some residents may even lead to unintended consequences as noted by the relative in the preceding quotation. Additionally, in practice nearly all the staff that were questioned did not believe that episodes of FI frequency can be improved among older people in care homes, particularly those with underlying dementia. Therefore, any good bowel care in care homes should prioritise giving as much information as possible on the potential for FI improvement (e.g., that FI can potentially be managed and reduced by intervention) to the care staff.

Only a few of the staff members did express a belief that it was possible to ameliorate FI in residents with dementia (Box 7, **Quote 4**). But even among those that believed something could be done to reduce FI in residents with dementia, they did not appear to understand the mechanism by which FI could be ameliorated:

> *"**Yes, we can** [reduce episodes of FI in residents with dementia]. It is **a tricky question to say how**."* [Group Interview 2: Staff Respondent 1]

In this study, the stakeholders seemed to understand that FI and dementia triggered care home admission for most residents:

> *"**I went to assess a gentleman who is now with us, he was living at home with his wife** being the main carer and **he was obviously starting to open bowels in different places in the house or taking a manual evacuation and smearing and probably hiding in certain places. And then obviously this was the trigger for the wife to say she couldn't cope**, but she didn't want him to come to any care home."* [FGD-MP4]
>
> *"Well, my husband I looked after him for about 2½ years and obviously his condition started to deteriorate, and it did end up that he was wearing pads."* [Group Interview 2: Relative 2]

There is also evidence to suggest that the staff do recognise the importance of bowel care because of the benefit to the resident and to the care staff themselves:

> *"…**when they [residents] are incontinent it can give them problems like pressure ulcers** and if the person is opening bowel too much it depends how you wipe the person, if you are scrubbing it out, or you are just patting it very. **Moisture lesions**, pressure ulcers."* [FGD-FP3]
>
> *"**It [bowel care] will help staff members because** like I say if we plan the toileting regime for people who are mobile, people with cognition, it will help staff as well. **The time that staff spend changing a resident**…because changing a resident **is not only one five minutes. It takes time** to clean them and make sure that they are cleaned and then dried. **So if the resident can now start using the toilet because of the toileting regime** that you put in place and start helping himself, **the staff can save time** as well. **The staff can use that time to do something else**"*. [Individual Interview-RN]

Overall, the finding suggests that when care staff do not believe that anything can be done to reduce FI episodes (C), this preconceived notion demotivates them to think about any management strategies (M) and as a result, FI is normalised (O). Conversely, when care staff believe that FI can be ameliorated by intervention (C), this encourages/motivates them to pursue management strategies (M), which could potentially promote continence (O).

6.10 How can a theory-driven intervention can incorporate care home routines that value and support care home staff, as well as fit within routines?

6.10.1 *Programme Theory 6: Making FI care integral to care home routines*

This programme theory argues that even if staff know about managing FI (C) and know about person-centred care practices for people with dementia (C), their capacity (C) to implement them will depend on how it fits (M) with the everyday work pattern and environment. Several different contexts (e.g., knowledge of FI, knowing the resident, appropriate staffing levels, availability of clinical expert input – geriatricians/GPs/continence nurses, belief continence can be improved and physical environment) will trigger 'doing the right thing' (M) and result in less FI and, most likely, dependent continence (O) (Goodman et al. 2017). These contexts may trigger other mechanisms, such as 'risk aversion' and 'pre-emptive pad use' that will not result in the desired outcomes. This area incorporates the ideas of staff balancing, juggling, and making 'trade-offs' in their everyday practice.

Box 8: Programme theory 6 (PT6)
Making faecal incontinence care integral to the everyday work pattern and environment (i.e., 'fit') will reduce faecal incontinence.

Quote-1: *"Then it's a routine as well like after breakfast they attend activities, so between 11.00am to 11.30am just to use the towel just to see that they are dried; wash their hands and then get them to the tables. Then in the afternoon it's after teatime or prior teatime, and then after supper."* [FGD-FP3]

Quote-2: *"so if I'm working on each wing, I need to ensure that the residents are being assisted to use [toilet] whether they are ready or not ready just to try to prevent them from having an accident because sometimes they feel bad as well when they are incontinent."* [FGD-FP7]

Quote-3: *"In advanced dementia Unit, we did have a resident who used to do faecal smearing. So that person used to wake at 5am and open her bowel and she was on ferrous sulphate so very blackish bowel. And if you didn't get to her at the right time and support her, she could paint the whole bathroom wall. She would paint it in multiples of colours"* [FGD-FP3]

Quote-4: *"She's very independent, she can go to the toilet and then she will forget it the next moment. Sometimes there are smears in the toilet that can give you a hint."* [FGD-FP1]

CMO = Episodes of FI can potentially be reduced (O) if care staff understand how dementia impacts continence care (C), and the staff incorporates person-centred care into everyday routines of the care home (C). The mechanisms are that staff will understand why individual residents behave in certain ways (M), thus enabling the staff to do the right thing (e.g., provide timely toileting assistance, change of incontinence pads, etc.) (M).

PT5 = programme theory 5; C = context; M = mechanism; O = outcome; CMO = context-mechanism-outcome; FP = female participant; FGD = focus group discussion; Quote = expressions of individual participant

The finding suggests routine work in the care home (Box 8, **Quote-1**), which is usually adapted to the individual resident's care needs (Box 8, **Quote-2**). The data supports that the stakeholders understood how dementia can affect the individual's ability to use the toilet (Box 8, **Quote-4**), and how important it is to individualised care amidst care routines (Box 8, **Quote-3**). The finding also suggests that episodes of FI in residents can potentially be reduced (O) if care staff understand how dementia impacts continence care (C), and the staff incorporates person-centred care into everyday routines of the care home (C). The mechanisms are that staff will understand why individual residents behave in certain ways (M), thus enabling the staff to do the right thing (e.g., provide timely toileting assistance, change of incontinence pads, etc.) (M).

Notwithstanding, the stakeholders believed that a multidisciplinary approach to care was important:

> *"**We handover to the registered nurse, and the registered nurse makes referral to the GP to review laxatives**. Or, if we have plan already in place, we try that plan first and if it is not working then we ask the GP to review"* [Group Interview 2: Staff Respondent 2]

> *“**Right now, we are all working together**…I mean, **Care Assistants, Nurses, the GP, the Kitchen staff and the domestic staff. You know everyone have their role to play**… the **staff need to work together as a team**. They all need to know that workplace is not somewhere to bring their differences.”* [Individual Interview-HCA]

There was strong support for inherent difficulties regarding incorporating person-centred care with continence care in residents with underlying dementia. Some of these expressions from the stakeholders (which are new understanding of PT6) are provided in Box 9 below:

Box 9: Challenges to incorporating person-centred care with continence in residents with dementia

Quote-1: *“we had another resident who used to walk…she used to walk and go in each room, open her bowel. So she was partially registered blind so she can’t make it to the toilet she would see an armchair and think that’s a toilet, she would just sit on it and open her bowels. So, you can’t keep their room locked because it’s their home.”* [FGD-FP3]

Quote-2: *“the hardest part is when the residents are fighting back during personal care especially when they are big and strong. So there are staff that they are complaining that they are not feeling comfortable and sometimes we are not restricting anyone here but you have to be extra careful with these ones to support them even more. But you don’t know that if you put more staff let’s say to go to the toilet or with this resident if it will make it worse or if it will be.”* [FGD-MP1]

Quote-3: *“So some of them will say well I don’t want to be supported, I don’t want to, so sometimes you have to accept. It depends on if they like you or they get on very well with you. Then you can support them because if they don’t like you it’s going to be really difficult for your job because they will say, no I don’t like you, I don’t want you to come near me. But at the same time, they need support from you because you can’t leave them like that. So it’s a little bit tricky but that’s the only way we manage it”* [FGD-FP]

Quote-4: *“We had someone sectioned because they became really aggressive and when they went to the hospital it turned out they were impacted.”* [FGD-FP4]

FGD = Focus Group Discussion; MP = Male participant; FP = Female participant

From practice observations, the study site seems to be doing particularly well with many care domains. For example, at the unit where this study was based, the care staff attended a ‘well-being’ meeting every Wednesday morning. During the meeting, two of the residents’ cases were reviewed, and the care staff were challenged to identify areas of potential improvement in the residents' care. The meeting potentially encouraged peer to peer learning. For example, during one of the ‘well-being’ meetings attended during this research study, a resident that was documented to have frequently declined personal care (including continence care) was discussed. It transpired that the resident allowed certain staff to assist her, but not other staff. Therefore, incorporating bowel care in care home routines through staff meetings, like the 'well-being meeting' described herein, may enable care staff to appreciate the potential for improvement in FI and may potentially encourage the staff to work towards providing good bowel care. This may potentially improve the nihilistic attitudes among the care staff regarding FI among older people with dementia because the care staff will understand the importance of their job.

6.11 Continence care outcomes considered as viable by stakeholders

The main goal of social care in care home setting is to provide improvement in well-being and quality of life for residents. So, for an intervention such as bowel care, an important goal is to determine outcome measures that would indicate improvement among care home residents.

The FINCH study identified three categories of outcomes: resident (e.g., continence or reduction in episodes of FI, skin integrity, dignity, and comfort), staff (e.g., increased knowledge, work satisfaction) and organisational (e.g., cost of resource use, reputation). This phase of the thesis focused on resident and staff outcomes because these are areas where the care home staff have a prospect of contributing to improvement.

The stakeholders' consultation identified resident outcomes as improvement in residents' skin integrity, reduction in episodes of FI (e.g., FI measured using bowel charts, or by incontinence pads count), as well as avoiding constipation and potential subsequent hospitalization. The staff outcome identified were accurate use of bowel charts (bowel diaries), as well as confidence in providing bowel care, especially for residents with dementia (and what staff describe as 'challenging behaviour', such as smearing of faeces). On the choice of bowel chart and skin integrity, a participant expressed:

> *"You can look at it from the bowel charts and then the skin integrity because they go hand in hand, don't they? We have a few problems with that on our units, or we have done at least with residents who are doubly incontinent or incontinent of either faeces or urine and what not. Sometimes it will lead to moisture lesions and then it can be uphill battle."* [FGD-MP3]

Pad count and overall reduction in episodes of incontinence were suggested by another participant who expressed:

> *"You can also say if the person is still requiring the same incontinent pad or bigger or smaller type, or if the incontinence is managed better."* [Interview – Care Assistant]

The staff outcome may also be assessed against their confidence and/or knowledge in providing individualised bowel care. These two indicators will potentially address other staff outcomes identified from the evidence, as indicated under various programme theories above, including avoidance of needing to use physical force, avoidance of the risk of being hit or even injured by non-cooperating resident, or the believe that continence care does not warrant training.

6.12 Discussion

The management of bowel movements (and continence care) is one of the main activities performed by the care homes staff (especially the care aides, also known as Care Assistants or Healthcare Assistants). However, bowel management as key skill remains under-recognised by carers and it does not seem to them to be professionally interesting, probably because it is often considered unrewarding, exhausting and repetitive (Ostaszkiewicz et al., 2016a) and often associated with limited time and human resources to carry out tasks (Seigneurin-Hérissé et al., 2022). Incontinence care is a dirty work (Ostaszkiewicz et al., 2016a) and involves emotional labour (Badolamenti et al., 2017, Gray, 2009, Huynh et al., 2008) for the carers that undertake the tasks. Therefore, care assistants need to apply strategies such as automatic emotional regulation and surface acting (e.g., management of visible aspects of emotions such as facial expressions, voice, and gestures) to avoid emotional dissonace (Zapf, 2002). The stakeholders' engagement in this realist evaluation extended the FINCH programme theories in terms of how continence care provided by junior staff should be valued to achieve residents' best outcomes.

Providing bowel care to older people living with dementia in care homes presents even greater challenge to the care staff because of how dementia impacts on residents (e.g., short-term memory or impaired cognition that makes it difficult to find the toilet, and/or poor dexterity and reduced mobility that can lead to functional incontinence) (Hagglund, 2010). Often due to ‘diagnostic overshadowing’ care staff miss important cues when a resident with dementia needs toilet assistance (e.g., care staff may attribute wandering and/or shouting to dementia when in reality the resident needs toilet assistance) (Dening, 2019, Dillane and Doody, 2019, Kerr et al., 2011). This research study highlights the need to provide specific bowel care particularly for older people living in care homes with dementia. The rationale is that many older people living in care homes do not have a formal dementia diagnosis (or documented dementia diagnosis) but are living with mild to moderate (and sometimes severe) cognitive impairment that may significantly impact their ability to appreciate the need to eliminate, recognise toilet facilities, undress, or respond to prompts from staff to use toilet.

The stakeholders’ engagement supports some of FINCH programme theories (PT1, PT3 and PT6), but provides less support for others (PT2, PT4, and PT5). For Programme Theory 2, data obtained does not support the existence of bowel care training, although the finding provided seems to suggest that such training is vital to improve continence care in the care home. Programme Theory 3 showed conflicting supports regarding routine activities as opposed to person-centred care in the care home. Programme Theory 5 provides support that suggests persistent existence of therapeutic nihilism (e.g., most of the care staff do not believe that anything can be done to improve episodes of FI among residents living with dementia in care homes.

The stakeholders’ engagement suggests that good bowel care for older people (particularly those with dementia) living in care homes requires involvement of clinicians in carrying out assessments (e.g., digital rectal examination), training, fluid and dietary input, exercise and medication review, and the potential for FI improvement when intervention is integrated into care home routines. The efficacy of clinicians involvement in continence assessment in care homes is missing in the literature (Hagglund, 2010). Nevertheless, the finding supports current national guidelines on managing FI in the general adult population, which recommends the involvement of healthcare professionals who have the relevant skills, training and experience to carry out baseline assessments that include anorectal examination (National Institute for Health and Care Excellence (NICE), 2007b). Additionally, the findings support the current NHS framework for enhanced health in care homes which advocates, amongst others, a multidisciplinary team support, including co-ordination of a range of health and social care services (Bayliss and Perks-Baker, 2016, National Health Services (NHS), 2020).

The stakeholders' engagement revealed that care home staff, both healthcare assistants (HCAs) and registered nurses (RNs), did not believe that they had permission to carry out invasive assessments such as digital rectal examination (DRE). A DRE involves first observing the peri-anal area for any abnormalities, including rectal prolapse, haemorrhoids, anal skin tags, anal lesions, scarring from episiotomy or tears, gaping anus, bleeding, faecal soiling, infestation or foreign bodies and general skin condition (Embleton and Henderson, 2020). It then requires the insertion of a lubricated gloved finger into a patient's rectum to assess the presence of faecal matter in the bowel, the amount and consistency of faecal matter, the need for rectal medication or the need for a digital removal of faeces in extreme cases of faecal impaction, and anal sphincter function and tone (Gaye, 2010). While the HCAs were correct in thinking so, the nurses were wrong in thinking that they were not allowed to carry out DRE. Certainly, registered nurses must acknowledge the limits of their professional competence and only undertake practice and accept responsibilities for those activities in which they are competent (Nursing and Midwifery Council (NMC), 2018). However, the ability of the nurse to undertake DRE is a fundamental nursing competency (Embleton and Henderson, 2020) because nurses have a professional responsibility to ensure no harm comes to their patients as a result of their actions or omissions (Nursing and Midwifery Council (NMC), 2015, Nursing and Midwifery Council (NMC), 2018).

In this realist evaluation, the data obtained suggests that care home staff do not receive specific bowel care training, and no participant mentioned nurse prescribing as a more responsive approach to medication management. Many respondents expressed the view that a bowel care training would be catalyst (or context) to provide better care because it would empower them with the skills to identify bowel problems and either confidently deal with it or make appropriate referral. The need to provide training and/or FI education to care home staff had previously been undertaken by other researchers (Blekken et al., 2015b). While staff education or training may enhance staff confidence and potentially also address the nihilistic concept among the staff (as evident under Programme Theory 5), it may not necessarily lead to better bowel management or reduction of FI episodes in practice (Goodman et al., 2017). There may also be the need to consider other factors such as the everyday routines of the care home, the work pressures, and managerial support in terms of staffing shortages (Programme Theory 6) that was observed in practice in this research study.

This research study found that the care home stakeholders understand some risk factors for constipation for older people with dementia living in care homes (Programme Theory 3). The stakeholders also appreciate that every resident is different and required individualised bowel care (Programme Theory 4). However, there was conflicting evidence on how person-centred care (PCC) was achieved in the care home amidst other constraints such as staff shortages, limited time to complete tasks, and the challenge inherent in caring for a resident with dementia who refuses staff assistance. This finding provides more granular account of how knowing what ought to happen is affected by ability of the resident (e.g., to eat and drink as they would want and the amount of time they can give to this activity). From the data, there was some evidence of staff saying that they were incorporating residents' choice in their care, and adhering to PCC approaches, but it was less so in practice. The activities in the care home seemed to be carried out in a task-oriented fashion. This finding is consistent with a study which found traditional practices (e.g., routine work) as a barrier to the implementation of PCC (Moore et al., 2017). There is also an inherent dilemma to incorporating PCC into continence care. Providing continence care (e.g., helping a resident to the toilet or altering the environment to prevent functional incontinence, or helping the resident with personal hygiene after an episode of incontinence) may necessarily involves transgressing the individual's personal space and infringing on his/her privacy and dignity (Northcott et al., 2022, Ostaszkiewicz et al., 2020).

This realist evaluation found residents' continence care outcomes (as suggested by the care home stakeholders) to include reduction in episodes of FI (e.g., measured by bowel charts), residents' skin integrity, and avoiding constipation and the staff outcome identified was staff confidence in providing individualised continence care. Although the stakeholders in this study suggested incontinence pad count as an outcome measure, previous studies have found pad count as a poor measure of urinary incontinence (Sacco et al., 2019, Tsui et al., 2013). There are also practical issues regarding differentiating pads with UI, FI, and/or DI. The care staff probably identified skin integrity as residents' continence care outcome because residents' skin integrity is currently an indicator of quality care (National Institute for Health and Care Excellence (NICE), 2015) and falls within safeguarding concerns (Department of Health and Social Care, 2018). Whereas continence care is not a quality care indicator (even though it needs to be because of its impact on the residents' quality of life). Interestingly, the national guidelines on risk factors for developing pressure ulcer (an altered skin integrity) within care homes include significant limited mobility, loss of sensation, a previous or current pressure ulcer, malnutrition, the inability to self-reposition, and cognitive impairment, but not incontinence (National Institute for Health and Care Excellence (NICE), 2015).

The new insights into the FINCH programme theories include the need to recognise and value the contributions made by care staff who spend more time with the residents and are familiar with the residents' care, including their bowel movement patterns. While the need for a clinician to take a lead for bowel assessment is evident, the clinician will arguably not know where to begin assessing the individual resident without the care staff careful observations and subsequent referral of the resident. The stakeholders' engagement suggests a need for bowel care training, but the content of such training remain unclear. Therefore, there is a need for an intervention in bowel care to consider the training need of the care staff. The finding also suggests that the care staff understand how to manage constipation, but there are inherent difficulties regarding dietary modification within the care home setting because some residents may have other comorbidities. Incorporating person-centred care into the care home routines is difficult, and so too is the involvement of some relatives into the care of the residents. There is an overall nihilistic belief among the care staff that it is not possible to reduce episodes of FI among residents living with dementia in care homes. There seems dissonance between what the care staff thought was possible (e.g., few care staff expressed that FI could be ameliorated by intervention) and what they believed about managing FI in older people living with dementia in care homes (e.g., even among the few care staff that expressed beliefs that FI could be ameliorated, they did not know how that could be achieved). This latter finding seems to support the 'emotional dissonance' care staff often display (Johnson, 2015, Rodriquez, 2011, Zapf, 2002) when carrying out tasks such as incontinence care (Dahle, 2005, Glerum, 2021, Ostaszkiewicz et al., 2016a, Soral et al., 2022).

6.12.1 Limitations

There was only one resident interviewed for this phase of the research study. Similarly, there were only two relatives interviewed during the stakeholders' engagement. While this may be viewed negatively, the PhD candidate took steps to ask staff members working with the residents to fully answer the research questions. The line of questioning during interviews began with a broader qualitative questioning to a more realist approach of conducting interviews, thus demonstrating rigour in data collection and relevance of the data collected. The small number of interviews and one focus group discussion is a limitation. Notwithstanding, qualitative research enquiry traditionally advocates for a small number of interviews but the precise number cannot be decided a priori (Corbin and Strauss, 2008, Guest et al., 2006). Unlike generic qualitative research, a realist evaluation does not assume data saturation (Saumore and Given, 2008). In practice, realist evidence cannot be confirmed or abandoned through data saturation obtained in number of qualitative interviews but through relevance and rigour (Pawson, 2013). The relevant factor is not on 'how many' people realists talk to but on unraveling 'who', 'why' and 'how' (Manzano, 2016). Nevertheless, considering that the PhD candidate employed observations during which staff members were asked to comment on their practice, this enabled examination of the FINCH programme theories in a care home setting and gave a perspective of how to design an intervention.

The focus group and the first semi-structured interview guides in this study did not follow realists' ways of questioning. This presented a challenge in finding appropriate answers for hidden mechanisms which would have otherwise been easier had realists' line of questioning been employed. Initially, the PhD candidate decided not to follow realist line of questioning to avoid the discussions with the care home staff seeming too academic because many of the care assistants in the care home where the study was conducted do not speak English as their first language. However, through supervisors' feedback, subsequent interviews were conducted using realist interviewing approaches.

6.13 Chapter summary

Realist evaluation starts with theory and ends with theory. Realist evaluation looks for what works, for whom, and how. In this chapter, the views of care home stakeholders were sought to refine and/or get deeper perspectives of the FINCH programme theories. The findings from the stakeholders' engagement provide more insights rather than refine the FINCH programme theories. As well as proving more insights on the programme theories, the experiences of those who are either involved in, or potentially affected by, bowel care in the care home is presented. The findings highlight the potential utility of the programme theories when developing an intervention for bowel care that accounts for care home residents' characteristics (e.g., comorbidity such as dementia) and the care environment. There data obtained from the stakeholders' engagement support Programme Theories 1, 3 and 6, but less support so for Programme Theories 2, 4 and 5. However, as the findings are context-dependent, translating the findings into practice need consideration of context. Realists believe that an intervention or programme that works in one context may not work in other contexts (or may even be harmful in other contexts).

In the next chapter, the findings from this realist evaluation, in conjunction with other evidence sources (Chapters 2 and 3) will be collated to develop an evidence-based, theoretically driven bowel care programme that will potentially resonate with the care home stakeholders.

PART THREE

Part-3 contains two chapters (Chapters 7 and 8): Chapter 7 collates the evidence from Chapters 2 and 3, in conjunction with findings from Chapter 6 to develop an intervention for bowel care; Chapter 8 presents the feasibility study.

Chapter 7: Intervention mapping and developing an intervention for improving faecal continence (ImFaCON) in care homes

This chapter is built upon the evidence established by two systematic reviews (Chapters 2 and 3) and the programme theories evaluated in Chapter 6. The chapter outlines the various components of a bowel care intervention and the justification for including each component in the intervention. The chapter then concludes by outlining the intervention procedures.

7.1 Introduction

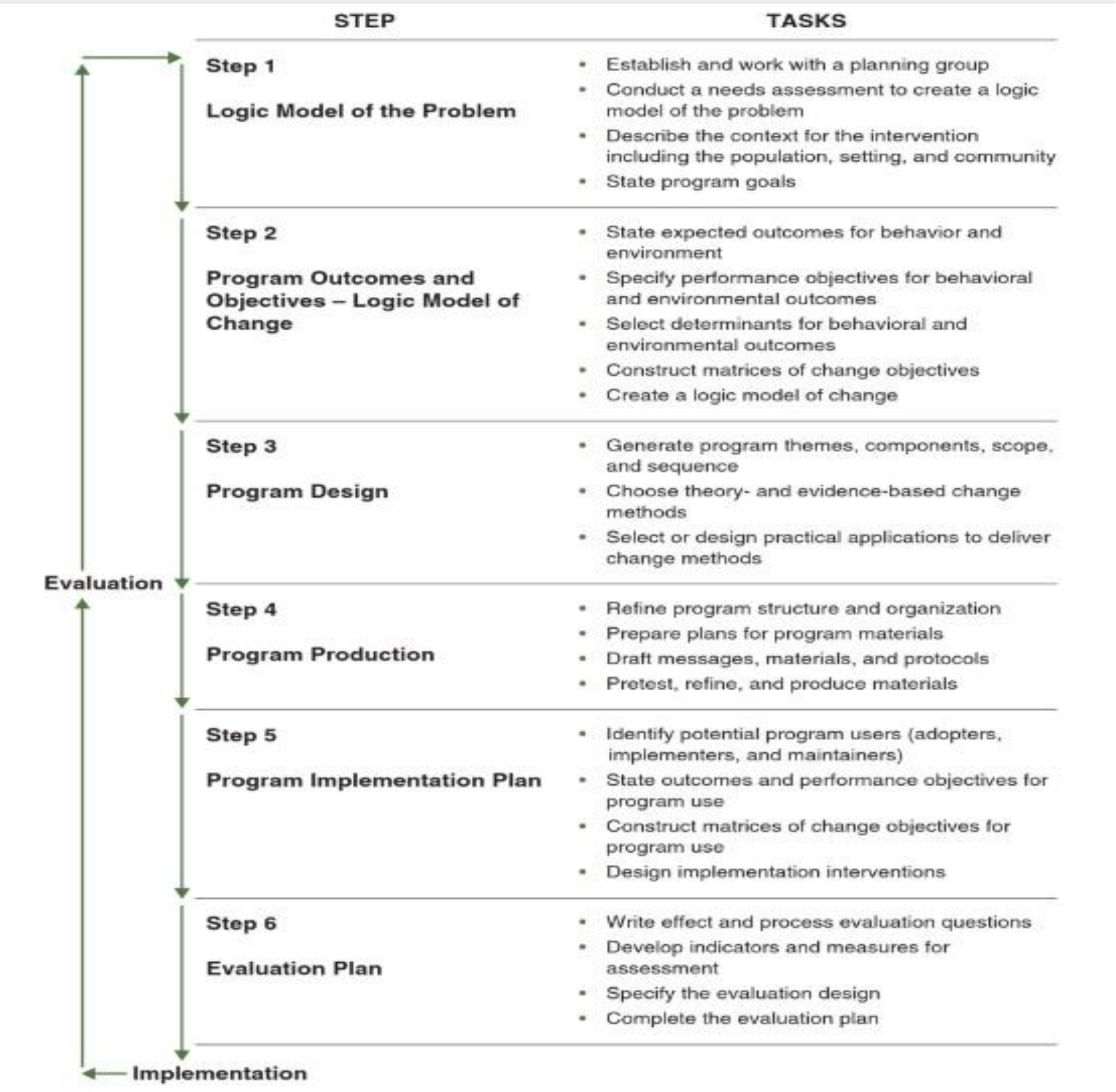
The UK Medical Research Council (MRC) introduced a framework as a guide for developing and evaluating complex interventions (Campbell et al., 2000), which has undergone two subsequent revisions (Craig et al., 2008, Skivington et al., 2021). The revised MRC frameworks offer a cyclic order of intervention development that include planning, development, feasibility and pilot testing, evaluation, and implementation (Craig et al., 2008, Skivington et al., 2021). The first phase of the second version of the MRC framework (intervention development) (Craig et al., 2008), which is followed in this thesis, involves the development of an intervention's theoretical rationale, often depicted in a 'logic model'. A logic model diagrammatically depicts the inputs that an intervention requires, the processes involved and the mechanisms via which these are intended to realise positive outcomes (Bartholomew-Eldredge et al., 2016, Bartholomew-Eldredge et al., 1998, Mills et al., 2019).

The intervention development phase of the second version of the MRC framework recommends identification of underpinning 'active ingredients' and how the intervention components are expected to synergistically interact with one another, and with the context of delivery (Craig et al., 2008, Craig and Petticrew, 2013). However, less emphasis is given to context in the first two versions of the MRC framework on how context impacts on outcomes (both intended and unintended outcomes) (Bonell et al., 2015). The second version of the MRC framework does not also recommend a particular template for a logic model to be used during intervention development.

Intervention mapping (IM) is a planning framework that provides a systematic process and detailed protocol for effective, step-by-step decision-making for intervention development, implementation, and evaluation (Fernandez et al., 2019). It provides guidelines and tools to ensure that an intervention or health programme is based on empirical evidence and sound theories (Dalager et al., 2019). Intervention mapping enables planners to systematically consider the following types of evidence: importance, causes (including behaviour and environment), and consequences of the health problem; effective approaches to behavioural and environmental change; and useful approaches to implementation (Bartholomew-Eldredge et al., 2016).

This PhD research study employs intervention mapping (IM) to bring together the evidence from two systematic literature reviews (Chapters 1 and 2) and findings from the stakeholders' consultation (Chapter 6) to develop a bowel care intervention. Intervention mapping is suitable for developing the intervention employed in this thesis because it directs planners to involve stakeholders in programme development and implementation; it also accommodates diverse perspectives and values in programme development and encourages informed decision making among individuals (Bartholomew-Eldredge et al., 2016).

Intervention mapping is an iterative process encompassing a six-step process: (1) logic model of the problem (or needs assessment); (2) programme outcomes and objectives (or identification of behavioural outcomes, performance objectives, and change objectives); (3) programme design (or selection of theory-based methods and strategies); (4) programme development; (5) programme implementation plan (or adoption and implementation); (6) programme evaluation plan (Figure 7.1). Therefore, the MRC framework and IM are complementary in terms of intervention development.



STEP	TASKS
Step 1 **Logic Model of the Problem**	• Establish and work with a planning group • Conduct a needs assessment to create a logic model of the problem • Describe the context for the intervention including the population, setting, and community • State program goals
Step 2 **Program Outcomes and Objectives – Logic Model of Change**	• State expected outcomes for behavior and environment • Specify performance objectives for behavioral and environmental outcomes • Select determinants for behavioral and environmental outcomes • Construct matrices of change objectives • Create a logic model of change
Step 3 **Program Design**	• Generate program themes, components, scope, and sequence • Choose theory- and evidence-based change methods • Select or design practical applications to deliver change methods
Step 4 **Program Production**	• Refine program structure and organization • Prepare plans for program materials • Draft messages, materials, and protocols • Pretest, refine, and produce materials
Step 5 **Program Implementation Plan**	• Identify potential program users (adopters, implementers, and maintainers) • State outcomes and performance objectives for program use • Construct matrices of change objectives for program use • Design implementation interventions
Step 6 **Evaluation Plan**	• Write effect and process evaluation questions • Develop indicators and measures for assessment • Specify the evaluation design • Complete the evaluation plan

Figure 7.1: Six steps of intervention mapping (Bartholomew et al. 2016, Chapter 1, p13)

This chapter focuses on the first four steps in the overall framework of IM to develop an intervention that is grounded in evidence and theory to address FI among older people living with dementia (OPLD) in care homes.

7.2 Step 1: Logic model of the problem (Needs assessment)

The first stem of IM is a careful description of the problem that will enable intervention planning (Fernandez et al., 2019). The aim of this step is to assess a health problem, including the related behavioural and environmental factors and its associated determinants (Jones et al., 2016). This provides the foundation for starting intervention development and should include (1) analysing the health and quality of life problems and their causes; and (2) defining the programme goals (Bartholomew-Eldredge, 2016). These need assessments encompass two components: a scientific, epidemiologic, behavioural, and social perspective of an at-risk group and its problems; and an effort to “get to know,” or begin to understand, the character of the group, its members, and its strengths (Bartholomew-Eldredge et al., 2016).

7.2.1 Defining the health problem, its impact on quality of life, and determinants

Faecal incontinence as a health problem affecting older people, especially those with dementia living in care homes, has been discussed in Chapter 1. To understand what causes FI (the determinants) and how it impacts on quality of life of older people, an extensive literature review of the prevalence, incidence, and correlates of FI among older people living in care homes was undertaken by the PhD candidate (Musa et al. 2019; PhD Paper 1). The review highlighted both modifiable risk factors (e.g., reduction in activities of daily livings, diarrhoea, urinary incontinence, constipation, reduced mobility, and the use of laxatives), and non-modifiable risk factors (e.g., advanced age and dementia) that are associated with FI (Musa et al., 2019). In this research study, potentially modifiable correlates are those factors associated with FI that an individual resident, nursing staff, or policy makers have the potential to improve.

7.2.2 Defining the intervention goals

In the IM framework, programme goals are defined as the changes to be made regarding the health, quality of life, behavioural, or environmental factors identified in the needs assessment (Bartholomew-Eldredge et al., 2016). Based on the first literature review described above, a further review was undertaken with the Cochrane Incontinence Group to determine the best available bowel care interventions for older people living in care homes (PhD Paper 2). The goal was to find potential studies that have addressed the identified modifiable risk factors to reduce FI in older people living in care homes. However, the Cochrane intervention review did not find clear evidence on what intervention works to reduce FI in this subgroup of the population. Therefore, the PhD candidate sought to develop a multicomponent intervention based on the evidence from the two systematic reviews, and findings from previously published programme theories (Goodman et al., 2017) to potentially reduce episodes of FI among this subgroup.

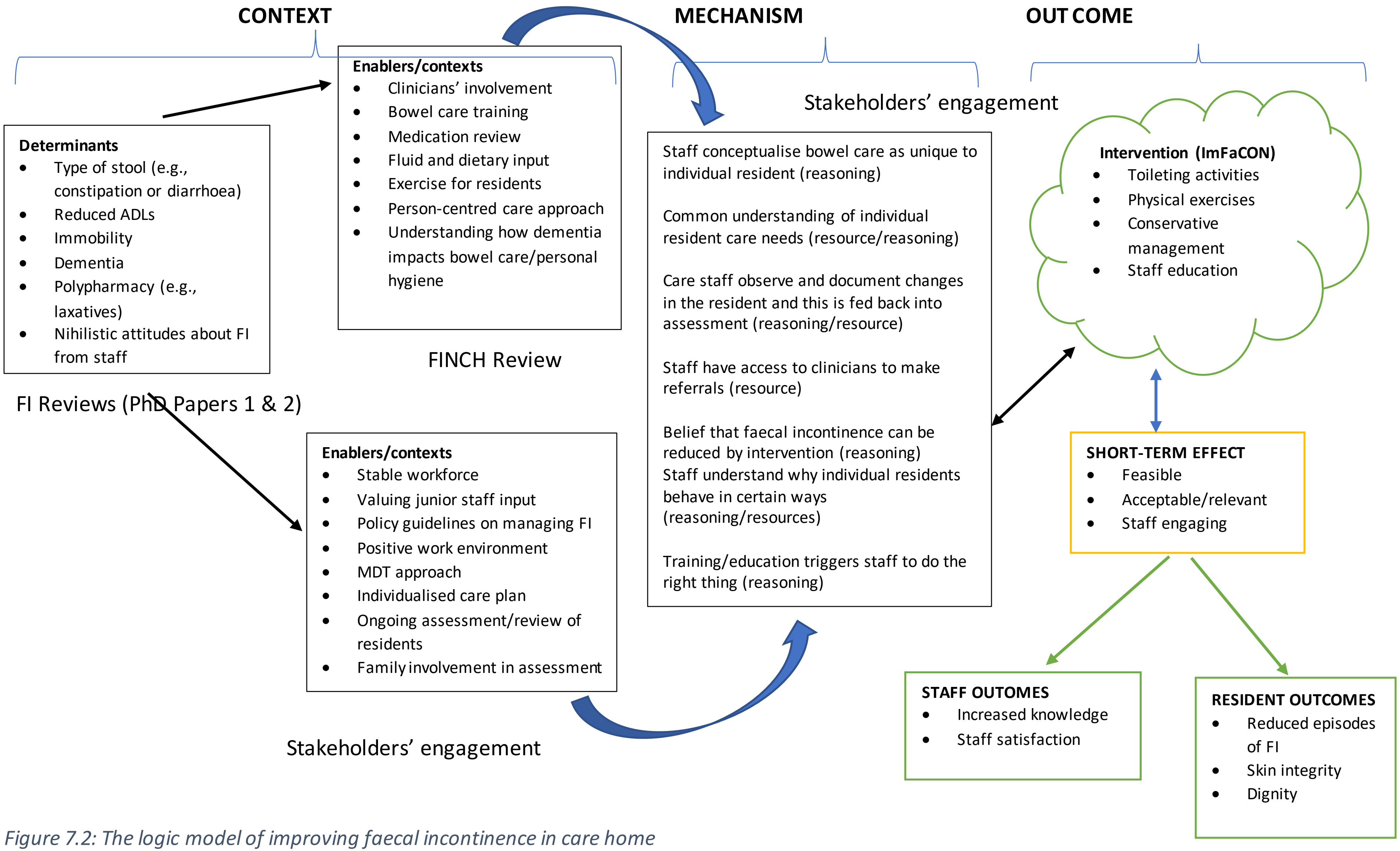
7.3 Step 2: Logic model of change (Identification of Outcomes, Performance Objectives, and Change Objectives)

The purpose of step 2 of the IM approach is to provide a focus for the development of the planned intervention by identifying what should change as a result of the intervention (Jones et al., 2016). In this thesis, the two literature reviews (PhD Papers 1 and 2) enabled identification of modifiable risk factors for developing FI and how to potentially address those risk factors as depicted in the logic model of change (Figure 7.2).

The first requirement for this step is identification of outcomes, which in the case of this PhD research study are twofold: residents' outcomes (reduction in episodes of FI, improvement in skin integrity, and providing comfort/dignity care) derived from the literature reviews, and staff outcomes (staff knowledge, satisfaction, and confidence in managing FI) derived from the FINCH review (Goodman et al., 2017) and stakeholders' engagement (Chapter 6).

The second requirement for the logic model of change is to identify performance objectives (POs). Performance objectives are identified from the overall programme goals to set out what needs to be accomplished by the individuals in the intervention to achieve the programme goals (Jones et al., 2016). In this study, the POs will include adherence to bowel care protocol guidelines (as will be detailed hereinafter) to provide continence care for OPLD in care homes. The care staff are to review individual residents to ascertain the need to apply a component of the intervention, or all of the intervention components based on individual resident characteristics.

The third requirement for the logic model of change is to identify the programme change objectives. Change objectives are the specific actions that would need to occur in order to achieve the performance objectives and programme goals (Bartholomew-Eldredge et al., 2016). In this study, the change objectives are expressed from the realists' stance as ‘mechanisms’ (e.g., resource and reasoning). Mechanisms are a combination of resources offered by the programme under study and stakeholders’ reasoning in response (Pawson and Tilley, 1997). In other words, the intervention in this thesis is aimed at unpacking the reasonings and/or resource requirements that may lead to reduction of FI episodes among older people living in care homes, when such an intervention is delivered within a particular context. A list of some potential generative mechanisms, when they interact with certain contextual factors, that may give rise to certain outcomes (foreseeable or not) is given in step 4 of the IM approach in this study (Figure 7.2). For clarity and easier comprehension of the figure, only positive outcomes are presented below in the diagram.



Determinants

- Type of stool (e.g., constipation or diarrhoea)
- Reduced ADLs
- Immobility
- Dementia
- Polypharmacy (e.g., laxatives)
- Nihilistic attitudes about FI from staff

Enablers/contexts

- Clinicians’ involvement
- Bowel care training
- Medication review
- Fluid and dietary input
- Exercise for residents
- Person-centred care approach
- Understanding how dementia impacts bowel care/personal hygiene

Enablers/contexts

- Stable workforce
- Valuing junior staff input
- Policy guidelines on managing FI
- Positive work environment
- MDT approach
- Individualised care plan
- Ongoing assessment/review of residents
- Family involvement in assessment

Staff conceptualise bowel care as unique to individual resident (reasoning)

Common understanding of individual resident care needs (resource/reasoning)

Care staff observe and document changes in the resident and this is fed back into assessment (reasoning/resource)

Staff have access to clinicians to make referrals (resource)

Belief that faecal incontinence can be reduced by intervention (reasoning)
Staff understand why individual residents behave in certain ways (reasoning/resources)

Training/education triggers staff to do the right thing (reasoning)

Intervention (ImFaCON)

- Toileting activities
- Physical exercises
- Conservative management
- Staff education

SHORT-TERM EFFECT

- Feasible
- Acceptable/relevant
- Staff engaging

STAFF OUTOMES

- Increased knowledge
- Staff satisfaction

RESIDENT OUTCOMES

- Reduced episodes of FI
- Skin integrity
- Dignity

Figure 7.2: The logic model of improving faecal incontinence in care home

7.4 Step 3: Programme Design (Selection of Theory-Based Intervention Methods)

Step 3 of the Intervention mapping approach involves identification of relevant theoretical methods that can contribute to achieving behaviour change objectives and the practical applications that can operationalise these methods (Fernandez et al., 2019, Jones et al., 2016).

This thesis has explored the trustworthiness of the FINCH programme theories (Goodman et al., 2017) through stakeholders' consultation (Chapter 6). Based on these findings, four of the programme theories (PTs) were chosen to guide this intervention development (Table 7.1). These programme theories were chosen because either they had more supporting evidence (PT1, PT3 and PT6) or they overlapped other programme theories (PT2 overlapped PT4 and PT5).

Table 7.1: FINCH programme theories with corresponding intervention components and CMO configurations

Theories	Interventions	Contexts	Mechanisms	Outcomes
PT3: Addressing the cause and prevention of constipation.	**Toileting exercises** - Scheduled toileting - Prompted toileting	Availability of individualised residents' care plan. Staff know the bowel patterns of their residents.	Staff check and modify residents' diet and fluid intake Staff support resident to toilet as regularly as stipulated in the resident's care plan.	Improved resident's dignity. Improved resident's skin integrity. Less constipation leading to impaction with 'overflow' FI.
PT3: Addressing the cause and prevention of constipation. PT6: When care of older people living with dementia and FI is integral to the work patterns of the care home and its staff.	**Physical exercises** - Mobility/ambulation	Resident is capable of walking to toilet (with or without staff support). Shared communication among staff and review of residents' needs.	Staff either prompt or support a resident to toilet. Staff encourage other forms of exercises such as walking in the garden to improve gut motility.	Reduced episodes of FI.
PT3: Addressing the cause and prevention of constipation. PT1: Clinical led support.	**Conservative management** - High fibre diet and improved fluid intake - Review of polypharmacy	Availability of fibre-rich snacks for residents. Accurate documentation of fluid balance and food intakes. Availability of Pharmacists or GP to clinically assess effect of medications.	Staff to prompt and support residents to increase their fibre and fluid intakes between meals. Clinicians to review resident medications regularly to address constipation and/or adverse effect of polypharmacy such as loose stools.	Reduced episodes of FI.
PT2: Ongoing teaching, review and feedback for care home staff on how to reduce FI.	**Staff education** - Bowel care knowledge - Attitude - Work culture	Care home staff observe and document the changes in the resident, and this is fed back into the assessment/review documentation process.	Increases staff awareness and involvement in continence care. Prompts staff to review residents' medication. Reminds staff to encourage fluid and nutrition intake. Triggers staff to involve residents in activities that reduce the risk of constipation (e.g., exercise).	Improved staff knowledge and confidence in continence care. Reduced episodes of FI.

Key: CMO = Context-Mechanism-Outcome; PT = Programme Theory; FI = Faecal Incontinence

7.5 Step 4: Programme Production (Organisation of Methods and Applications into an Intervention Programme)

Step 4 of the IM approach involves the development of the actual intervention programme components and materials that are to be delivered to participants (Bartholomew-Eldredge et al., 2016). This framework ensures that the intervention meets the objectives, which are outlined in step 2 and fits the requirements of practical applications (e.g., mechanisms) as identified in step 3 (Jones et al., 2016).

In this PhD research study, hereafter styled ImFaCON (Improving faecal continence), the intervention components to be operationalised are toileting exercises (supporting a resident with dementia to go to toilet: prompted or scheduled toileting), physical exercise (mobility/ambulatory and upper arms movement), conservative management (dietary and fluid intake, and review of polypharmacy), and staff training. How each of these components will address bowel management in practice is summarised in Table 7.2 below. First, the rationale for choosing the various components of the intervention is outlined in the next section.

Table 7.2: ImFaCON components with corresponding programme theories and Implementation strategies

Intervention components	**Programme theories (PTs) from FINCH review**	**Implementation strategy**
Toileting exercises • Scheduled toileting • Prompted toileting	PT3: Addressing the cause and prevention of constipation.	Staff to individualise residents' bowel care plan, taking into account the residents' bowel patterns. The staff also need to consider individual resident's diet and fluid intake, as well as review of medication (e.g., effect of opioids) to prevent or manage constipation.
Physical exercises • Mobility/ambulation	PT3: Addressing the cause and prevention of constipation. PT6: When care of older people living with dementia and FI is integral to the work patterns of the care home and its staff.	Incorporating into a resident's care plan activities such as helping him/her to either walk or use wheelchair to the toilet, or around the garden can help to improve gut motility (and to get to toilet in time and to sit with stability) and this in turn can promote normal bowel opening (with reduced constipation). When care of older people living with dementia and FI is integral to the work patterns of the care home and its staff, bowel problems such as constipation, diarrhoea, and/or FI among residents can readily be detected and managed promptly and appropriately.
Conservative management • High fibre diet and improved fluid intake • Review of polypharmacy	PT3: Addressing the cause and prevention of constipation. PT1: Clinical led support.	Introducing high fibre diet and encouraging adequate hydration can improve gut motility and reduce constipation. The involvement of clinician (e.g., nurse, pharmacist, or GP) is required to review polypharmacy which sometimes are the cause of constipation, diarrhoea and/or the resultant FI.
Staff education • Bowel care knowledge • Attitude • Work culture	PT2: Ongoing teaching, review and feedback for care home staff on how to reduce FI.	Ongoing teaching, review and feedback for care home staff on how to reduce FI will impact on how they view and prioritise bowel care.

Key: PT = Programme Theory; GP = General Practitioner; FI = Faecal Incontinence

7.6 Step 5: Programme Implementation Plan (Rationale for the chosen components of bowel care intervention)

Bowel management among older people living in care homes is discussed here under three broad subheadings: the need for staff education in bowel care, addressing constipation, and addressing faecal incontinence. The first of these emerged from the literature, while the latter two sub-categories emerged from how stakeholders understood what the bowel problems were in the care home where this study was carried out.

The need for staff education in bowel care: The level of awareness among healthcare personnel regarding appropriate assessment and treatment options for bowel care among older people living in care homes seems limited (Blekken et al., 2016, Norton et al., 2010). Therefore, the inclusion of a staff training programme in this thesis is in accordance with recommendations from the International Continence Society on the need to educate healthcare providers to heighten awareness of FI, including methods of bowel problems identification, assessment, and management in older people (Appendix 23 gives the context of the staff training programme developed). The FINCH review by extension, highlighted that the focus of an intervention in this subgroup of the population should be on junior and least qualified staff who provide most intimate and hygiene related care (Goodman et al., 2017).

Addressing constipation: constipation is not a disease, but a general term that is used to describe the difficulties that people experience with moving their bowels (McCrea et al., 2008). It is defined by straining or incomplete defaecation and/or rare bowel movements (every three to four days or less), according to the Global Guidelines of the World Gastroenterology Organisation (Lindberg et al., 2011). Most people with a complaint of constipation have a functional disorder that affects the colon and/or anorectum (Andrews and Storr, 2011). The term “functional” is used to describe symptoms or problems that have no underlying anatomic abnormalities, or other pathophysiological abnormalities such as bowel disease or neuropathy (Arco et al., 2022). Functional constipation is defined as the reduced frequency of bowel movements and/or an altered act of evacuation (e.g., incomplete defaecation) (Arco et al., 2022, Drossman, 1999).

Constipation in this thesis is considered as the passing of hard stool in older people (e.g., (Bristol stool types 1, 2 and 3), which is characterised by infrequent defaecation (e.g., fewer than three episodes of defaecation per week) and difficult evacuation of stool (Chen et al., 2020, Lindberg et al., 2011). However, it is acknowledged that less than three episodes of defaecation per week may be considered normal if this does not represent a change from the usual frequency of baseline defecation events, and defaecation is not associated with excessive straining or discomfort. For this reason, a Bristol stool chart will be used as a guide (Continence Foundation of Australia, 2020), in combination with a bowel diary, considering stool consistency and frequency, and whether straining is documented by care givers (Patel et al., 2016, Saga et al., 2014, Takaoka et al., 2020).

A) ***Dietary fibre and water intake***: Several studies have shown that the CTT was shortened, and the stool frequency increased when the amounts of dietary fibre and water intake increased (Cheskin et al., 1995, Cho et al., 2013, Davies et al., 1986, Metcalf et al., 1987). However, results and data from studies evaluating relationships between constipation and dietary fluid and fibre intake, are inconsistent (Yurtdaş et al., 2020). For example, some researchers support the relationship between constipation and dietary fibre intake (Chan et al., 2022, Sandler et al., 1990, Yurtdaş Depboylu et al., 2022), whilst others report no effect of dietary fibre intake in subjects with constipation (Dreher, 2018, Klauser et al., 1990). Therefore, this component of the intervention hypothesises that adequate fluid intake in addition to dietary fibre intake can help to reduce symptoms of constipation. The reason is that softer stool is easier to pass during defaecation and less likely to become impacted leading to overflow diarrhoea. Softer stool is more likely to result to complete emptying of the bowel.

An ideal daily intake of calories varies depending on factors such as age, metabolism, and levels of physical activity, but generally the recommended daily calorie intake is 2,000 calories a day for women and 2,500 for men (National Health Services (NHS), 2019). The National Health and Nutrition Examination Survey 1999-2002 suggest that snacking episodes occur approximately twice per day on average and account for 20% of daily energy intake in women (Kant and Graubard, 2006). In one study investigating the influences of snack selection on nutritional intake, triglycerides, and bowel habits, it was reported that dried plums promoted a softer stool consistency compared with usual dietary intake and, or intake of low-fat cookies (P≤0.05) (Howarth et al., 2010).

Not drinking enough fluids can result in increased risk of repeated urinary tract? infections, falls and constipation, secondary to dehydration. It can also lead to confusion, headaches and irritability (Welsh Government (WG), 2019). Older people are at risk of being dehydrated because of ageing. Their kidneys may not function as well as younger people, and some of them may not have a sense of thirst or be able to communicate that they are thirsty due to underlying dementia. In one study conducted in care homes to understand the complex nutritional problems associated with eating and drinking for people with dementia, the authors reported that development of person-centred nutritional care emerged as the overarching theme, followed by availability of food and drink, resources and environment, relationship of residents to others when eating and drinking, residents' participation in activities, and consistency of care delivered by the care staff (Murphy et al., 2017). However, a systematic review of twenty included studies identified challenges of supporting nutrition and hydration, balancing the views of all parties involved in the care of the person living with dementia regarding 'the right thing to do', and reported? sociocultural influences as barriers to promoting nutrition and hydration in people living with dementia (Barrado-Martín et al., 2021).

The recommended amount of water per day for adult is 6 to 8 cups or mugs, which is approximately 1600ml to 2000 ml per day, based on a 250ml mug (Welsh Government (WG), 2019).

B) ***Exercise***: Anecdotal experience suggests that exercise accelerates gut motility. Roald Dahl summarised this in the first stanza of his poem "Goldilocks and the three bears":

> “*An early morning strolls*
> *Is good for people on the whole*
> *It makes your appetite improve*
> *It also helps your bowels to move*” (Dahl, 1985).

Empirically, peristalsis of the intestines is activated by physical exercise, and this shortens the CTT (Cronin et al., 2018, Mailing et al., 2019, Song et al., 2012). Peristalsis of the intestines is promoted or increased by the increase of prostaglandin within the body (Song et al., 2012, Zhao et al., 2021). Prostaglandin is a hormone that is involved in the synthesis of bile acid, cholesterol converted into the bile acid in the liver, and substances involved in tumour growth, such as interleukin-1, are affected by physical exercise (Molinero et al., 2019, Ridlon et al., 2014).

There is some research in support of low-intensity physical activity as a treatment for some types of constipation (Kim et al., 2014, Song et al., 2012). In the American Gastroenterological Association's 2013 technical review on constipation, it is stated that physical inactivity is a risk factor for constipation and that mild exercise increases intestinal gas clearance (Bouchoucha et al., 2019). Recent research studies have shown that low physical activity and a sedentary lifestyle are associated with constipation (Yurtdaş et al., 2020), and that exercise can reduce symptoms of constipation (Gao et al., 2019).

C) ***Medication review:*** The side effects of some medications have been reported as one of the most important causes of constipation (Davies and O'Mahony, 2015, Every-Palmer et al., 2017, van Dijk et al., 1998). The use of drugs remains high among older people living in care homes (Al-Jumaili and Doucette, 2018, De Giorgio et al., 2021, Halvorsen et al., 2010). However, it must be emphasised that the use of drugs in general, including polypharmacy, is not intrinsically the contributing factor for constipation in older people, but rather it is certain types of drugs. Drugs such as urinary antispasmodics, tricyclic antidepressants and some antihistamines increase the risk of constipation because of their anticholinergic properties (Gustafsson et al., 2019) and the use of opioid analgesics is a risk factor for the development of constipation in the elderly in long-term care (Chokhavatia et al., 2016, De Giorgio et al., 2021). Opioid-induced constipation is believed to be the most common adverse drug effect from opioid analgesics (Chen et al., 2020, De Giorgio et al., 2021, Gustafsson et al., 2019) and is estimated to affect 15–90% of patients prescribed these drugs (De Giorgio et al., 2021, Lämås et al., 2017, Rauck et al., 2017).

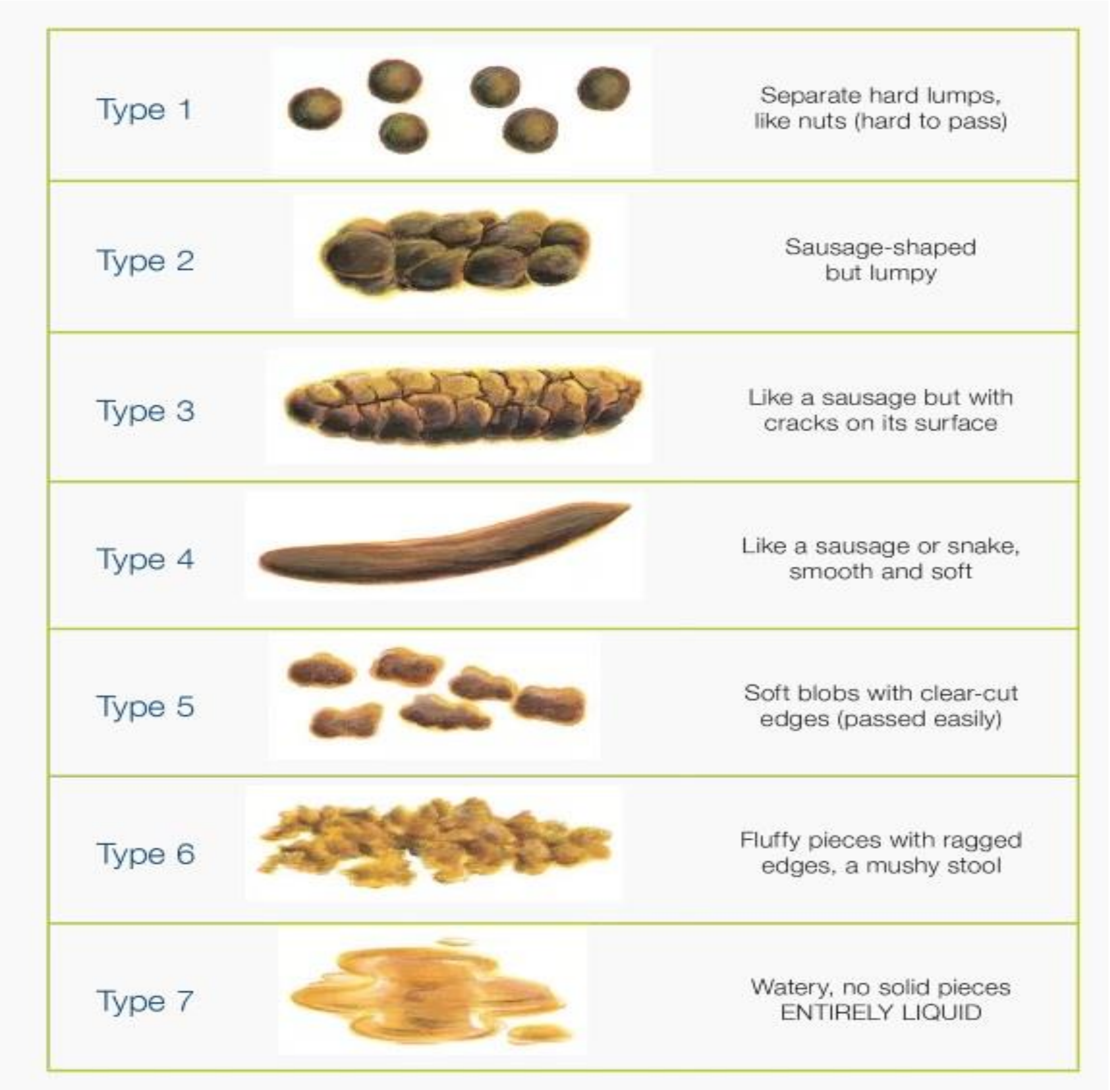
In one study, it was found that antidepressants (OR 3.08, 95% CI : 1.09–8.68, P = 0.03), and benzodiazepine derivatives (OR = 2.80, 95% CI : 1.12–7.04, P = 0.03) were significantly associated with constipation, and drugs with markedly anticholinergic effect (OR = 3.7, 95% CI : 0.78–17.53, P = 0.10), natural opium alkaloid (OR = 5.01, 95% CI : 0.95–25.94, P = 0.06), and propionic acid derivatives (OR = 7.00, 95% CI : 0.75–65.08, P = 0.09) also showed a correlation with constipation (Fosnes et al., 2012). The constipating effect of these drugs is known from several studies and reviews (Gallagher and O'Mahony, 2009, Rao and Go, 2010, Talley et al., 2003). This suggests the need for residents’ medication review by clinicians such as Pharmacists and/or General Practitioners, with focus on specific groups of drugs which might be contributing to constipation. During the intervention in this thesis, residents will be referred to the care home pharmacists and/or GPs for medication review where the need to do so becomes obvious.

In most care homes, constipation is treated with stimulant laxatives, bulking agents and osmotic laxatives (Gustafsson et al., 2019, Marfil et al., 2005), although there is little evidence to support the efficacy of these medications (Schnelle et al., 2010). Stimulant laxatives include bisacodyl, senna, and sodium picosulfate and these exert their effects by increasing muscle contractions via an enteric reflex (Chokhavatia et al., 2016). Bulking agents such as sterculia gum and ispaghula increase the water absorption properties of the stool (Mounsey et al., 2015). Osmotic laxatives include lactulose and polyethylene glycol (PEG) (Gustafsson et al., 2019, Mounsey et al., 2015), which increase the fluid content of the bowel lumen in order to hydrate and soften the stool (Gustafsson et al., 2019). Inappropriate use of laxatives could result in loose stool, diarrhoea and subsequently FI. Therefore, the approach to managing bowel problems such as constipation and diarrhoea should be individualised (Fleming and Wade, 2010).

Faecal incontinence: The aetiology of faecal incontinence has already been covered in Chapter 1. It includes loose stool and/or diarrhoea.

Addressing loose stool/diarrhoea: Diarrhoea is when a person passes watery or loose stool. The Bristol Stool Chart is an aid developed in 1997 as a clinical assessment tool that helps to describe seven types of stools (Figure 7.3). Type 1: This stool type indicates constipation, and that the person may not be able to completely empty their bowel or may do so with difficulty. There may also be bleeding associated with passing this type of stool. Type 2: This stool type appears log-shaped but lumpy. Type 3: This stool has the same characteristics as Type 2 stools, but the stools are easier to pass. Type 4: This is a normal stool. Type 5: These stools are normal as well. They are typical for a person who has bowel movements 1-3 times a day. Type 6: This stool type is considered as borderline normal. These kinds of stools may suggest a slightly hyperactive colon, or loose stool due to excessive laxative use. Type 7: This type of watery stool is classed as diarrhoea due sometimes to an infection or any other condition affecting the gut, or overuse of laxatives. It can also be a result of overflow with severe constipation.

Overall, Types 1, 2, and 3 indicate constipation, Types 4 and 5 are “ideal stools” as they are easy to pass, and Types 6 and 7 may indicate urgency or diarrhoea. This research study, therefore, categorises stool consistency as Type 1-3, Type 4&5, and Type 6&7 stools accordingly.



Type 1	Separate hard lumps, like nuts (hard to pass)
Type 2	Sausage-shaped but lumpy
Type 3	Like a sausage but with cracks on its surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges (passed easily)
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces ENTIRELY LIQUID

Figure 7.3: The Bristol stool chart (Continence Foundation of Australia, 2020)

Chronic diarrhoea is defined as loose stools that last for at least four weeks (Lamont, 2021). This usually means three or more loose stools per day. There are many possible causes of diarrhoea (e.g., irritable bowel syndrome (IBS), inflammatory bowel disease (i.e., Crohn's disease or ulcerative colitis), malabsorption syndromes in which food cannot be digested and absorbed, acute infections (i.e., norovirus, campylobacter, and Escherichia coli), and side effect of some medicines (e.g., laxatives, artificial sweeteners such as sorbitol, prescription and non-prescription drugs, herbs, and dietary supplements). Treatment is aimed at correcting the cause of the diarrhoea (whenever possible), firming up loose stools, and dealing with any complications of it (Lamont, 2021).

Older people, who often underestimate their stool frequency, frequently plan their days around their bowel movements, and treatments often precipitate loose stools and incontinence (Bouras and Tangalos, 2009).

7.7 Components of ImFaCON care

Toileting exercises

This component is designed to be individualised to a resident's needs, as every person is different. The staff need to collect resident's bowel history (if the resident is new to the care home, this history may come from family members, or the resident's previous carer) and record a bowel diary for at least a month. The aim of this component is to improve residents' mobility, thus leading to improved constipation through residents having regular bowel movements (using toilet facilities), and/or reduction in episodes of FI. Staff need to use the algorithm (Table 7.3) to determine whether this component of the intervention is appropriate or not for a resident. It may include a single or combined measure as follows:

1) Prompted toileting – depending on the bowel habit of a resident (e.g., frequency of bowel movement) and functional abilities (e.g., ability to mobilise to toilet), staff to prompt the resident to use the toilet (when he/she needs to according to their bowel diary and episodes of FI) during day shift (e.g., 07:30 to 19:30). This should be individualised in the resident's care plan. Evidence suggests that prompted-voiding is highly effective with urinary incontinence (Siswoyo et al., 2021), but much less effective with FI (Ouslander et al., 1996b, Schnelle et al., 2010, Simmons and Schnelle, 2004). The FINCH review recommends management of FI to also include management of urinary incontinence because both are intrinsically linked (Goodman et al., 2017). For this reason, it is recommended for this component to be used in conjunction with other components as proposed herein. This type of intervention is consistent with recommendations made by national guidelines (National Institute for Health and Care Excellence (NICE), 2007b, National Institute for Health and Care Excellence (NICE), 2014, National Institute for Health and Care Excellence (NICE), 2021), and international guidelines (Landefeld et al., 2008) on preventing FI.

2) Scheduled continence care – for a resident who is nursed in bed, and/or for whom there are no apparent patterns of his/her bowel habits (regardless of functional abilities), continence care (e.g., staff checking continent pads and cleaning up a resident when he/she is incontinent at a regular intervals or supporting him/her to use toilet at regular intervals) to avoid a moisture lesion or pressure ulcers due to FI. The use of incontinence pads between scheduled continence care is recommended to ensure comfort and/or dignity for the resident.

Physical exercise

This component is to increase activity and functional ability of a resident, as well as improve CTT (Cho et al., 2013, Howard et al., 2008, Yurtdaş et al., 2020). The choice of this component should be determined by staff based on the individual resident characteristics (Table 7.3). It requires the care staff to do the following:

1) Staff to individualise exercise activities, e.g., some residents may be able and prefer to walk round the garden twice a day.

2) Before or after incontinence care, staff to encourage the resident to walk or, if non-ambulatory, to wheel his/her chair and to repeat sit-to-stands up to eight times using the minimum level of human assistance possible (Bates-Jensen et al., 2003).

3) Resident to be encouraged to exercise (repeat sit-to-stands and walking or wheelchair propulsion) for up to 5 minutes between 6 to 8 times during day shift (e.g., 07:30 to 19:30) (Bates-Jensen et al., 2003, Schnelle et al., 2010).

4) Residents nursed in bed to be given upper body resistance training (arm curls or arm raises) after every episode of continence care, or between 6 to 8 times (whichever is more frequent) during day shift (e.g., 07:30 to 19:30).

Conservative management

This component ensures management of constipation, or loose stool which can sometimes be a precursor to FI. The choice of this component should be done taking into consideration the needs of a resident (Table 7.3). Activities of the component include:

1) Review of residents' care plan by a clinical lead (e.g., a nurse or experienced Healthcare Assistant) (Goodman et al. 2017) at least once in 14 days to address problems associated with polypharmacy and overuse of laxatives and/or drugs which causes constipation. The 14-day period will help the reviewing clinician to look at the bowel pattern of the individual resident, considering whether the resident is experiencing constipation or diarrhoea. The time frame may also help the clinician to assess whether or not loose stool is likely to continue for another two weeks to qualify it as "chronic diarrhoea", and to promptly take appropriate action such as referring the resident to his/her GP for help. Chronic diarrhoea is a diarrhoea that lasts for more than four weeks or comes and goes regularly over a long period of time. If such bowel problem is not resolved quicky, it may result in dehydration among very old people (many of whom have many comorbidities) and this can lead to serious complications of their health.

2) In between meals, staff to offer resident a choice of high fibre snacks three times per day between to increase fibre intake (Schnelle et al., 2010).

3) In between meals, staff to verbally prompt and support a resident with a drink eight times per day to increase fluid intake (Simmons et al., 2001).

Staff education

This component aims to serve as a resource for staff to either learn new skills or re-familiarise themselves with necessary information that may help them to confidently carry out bowel management. Every staff member to attend at least one online or face-to-face training session during the eight weeks study period. The training and/or learning resources to cover:

1) Staff knowledge – evidence-based information on managing FI (e.g., leaflets, brochures, and/or PowerPoint presentations) (Appendix 23).

2) Staff attitudes – towards delivery of care (e.g., online, or face-to-face training). Emphasis here will be on enabling staff to understand that bowel problems among older people living with dementia and FI is not an inevitable consequence of aging alone, but there may be other modifiable factors.

3) Skills – ability to apply evidence-based information to individualised case (e.g., online or face-to-face training). This information will be based on the types of stools as described by the Bristol Stool Chart.

Table 7.3: ImFaCON algorithm

	YES	NO
Does the staff member feel confident in supporting a resident who experiences faecal incontinence and has underlying dementia?		Attend training session on bowel management
Is the resident mobile independently, or with staff support can the resident use a commode?	Prompted toileting	Scheduled toileting
Is the resident's mobility restricted (e.g., wheelchair user, or bedbound)?	Scheduled toileting	Prompted toileting
Do you know the bowel pattern of your resident from the resident's bowel diary and/or other documentations?	Prompted toileting	Scheduled toileting
Does the resident have a particular activity of interest?	Promote that activity	Engage low intensive physical exercise
Does the Malnutrition Universal Screening Tool (MUST) score for your resident indicate dehydration?	Increase fluid intake	
In between meals, is your residents having snacks that are rich in fibres?		Promote fibre intake
Is your resident experiencing constipation despite interventions?	Refer resident for clinical review	
Is your resident having non-infectious diarrhoea/loose stool?	Refer resident for medication review	
Is your resident having more than two medications, some of which are opioids, Antiparkinsonian drugs, Antiarrhythmics, or Iron supplements?	Refer resident for medication review	

7.8 Step 6: Evaluation plan (Mode of delivery of ImFaCON care)

Care home residents

All care home residents living in two units identified as Dementia Care Units were eligible to participate. This study was due to commence prior to the outbreak of the Coronavirus (Covid-19) pandemic. Plans to carry out the study were suspended due to national Covid-19 restrictions. Due to ongoing infection control measures during Covid-19, the intervention delivery was modified as multiple case studies, with the PhD candidate consulting the care home staff remotely and visiting the care home once a week. This would not have sufficed had there not been outbreak of Covid-19. Residents were purposively selected by the care staff based on their knowledge of working with the residents (and the likelihood of the staff working with the individual resident).

The study lasted for ten weeks inclusive of recruitment period (that is, two weeks of recruitment period plus eight weeks of intervention period). The eight weeks intervention period was decided due to time constraints on completing the PhD after the most severe Covid-19 national restrictions. During the first two weeks, a series of meetings (both virtual and face-to-face meetings) were convened with the care home staff to aim to agree on individualised bowel care plans for residents who were to be enrolled in the case studies. A 4-week baseline bowel data and staff confidence level in bowel care were collected during the first two weeks of the study period. This was followed by 8 weeks of the intervention period during which study activities were carried out.

During the study period, study activities were monitored and captured by the paper case report form (CRF) (Appendix 24) developed by the PhD candidate in conjunction with the Person-centred Care Software (PCCS) (Aspire Care, 2021), which was recently rolled out in the care home where the study was conducted. The PCCS application is a digital care system specifically designed to allow staff to spend more time with service users and less time on administrative activities. Its function includes: (1) care planning, which encompasses incorporation of service users' preferences and delivery of person-centred care; (2) care monitoring which enables managers to track important actions, monitor the effectiveness of care and improves the implement up-to-date care delivery; and (3) group reporting, which enables analysis of trends and measurement of business critical key performance indicators (KPIs) for a single care home, or comparatively across a group of care homes (Aspire Care, 2021).

At the end of the 8 weeks, the PhD candidate again collected a set of routinely collected electronic bowel diaries on PCCS and staff confidence and knowledge levels to analyse the study's effect.

Care home staff

All care home staff that were involved in providing personal care (Registered Nurses and Care Assistants) were eligible to participate in the study. For staff members who were not enrolled into the study during Phase-1 of the study (Stakeholders' Engagement), the PhD candidate used the recruitment process described in Chapter 6.

Prior to the intervention, the PhD candidate met with staff and took baseline information to assess staff members' knowledge and confidence in bowel care (Appendix 25). This was followed by two sessions of PowerPoint presentations by the PhD candidate (Appendix 26) to help staff understand the study manual (Appendix 27) which had been designed to help staff understand the rationale for the research and the research process. The study manual was designed to serve as a resource for staff and it was left on each participating unit for the staff to use.

At the end of the intervention, the PhD candidate again met staff members to assess their knowledge and confidence (Appendix 23). This enabled the PhD candidate to assess the impact and the likely sustainability of the intervention that had been introduced.

7.8.1 Residents and staff outcome measures

Residents' outcome measures: This was measured using residents routinely collected electronic bowel diaries via PCCS on a two-weekly basis.

Qualifying the type of FI and quantifying its severity is important because it allows a reproducible measure of the degree of incontinence and to evaluate treatment response, compare outcomes for different interventions, and assess impact of FI on quality of life (Abou Khalil and Boutros, 2022). Thus, reliable, and valid symptom assessment tools are needed to evaluate FI for clinical and research purposes. There are three broad categories of FI assessment tools, namely: grading scales, FI impact measure, and FI severity scales.

Examples of FI grading scales include scales such as Parks' (1975), which grades FI as "A" for being continent to stool including liquid stool and flatus, "B" for being continent to solid and liquid stool but not flatus, and "C" for being continent to solid but not liquid stool or flatus.

Williams' (1991) scale assigns: 1 for being continent to solids, liquids, and flatus; 2 for continent to solid and liquid stool but not flatus; 3 for continent to solids but occasional liquid incontinence; 4 for occasional episodes of incontinence of solids and frequent episodes of incontinence to liquid; and 5 for frequent episodes of incontinence of solids and liquids. However, these scales were used in research papers to report on outcomes of specific treatments for FI and validation.

The FI impact measures include the FI quality of life (FIQL) (Rockwood et al., 2000), which was developed by the American Society of Colon and Rectal Surgeons in 2000 and contains four domains (lifestyle, behaviour, depression/self-perception and embarrassment) each containing up to 10 questions. It is a validated questionnaire but requires self-reporting (e.g., self-perception and embarrassment) and not fit for the study population that all had dementia and unable to engage with such assessment mentally and verbally. Another example of the FI impact measure is the Low Anterior Resection Syndrome (LARS) (Lee et al., 2015). However, LARS is used for patients after rectal surgery.

There are two widely used FI severity scores: the Wexner or Cleveland Clinic Florida Incontinence Score (CCFIS) (Jorge and Wexner, 1993), and the Vaizey or St.Mark's incontinence score (SMIS) (Vaizey et al., 1999). Both CCFIS and SMIS are validated scores and are widely used. However, the SMIS score also includes anti-diarrheal medication use and fecal urgency making it the preferred FI severity score for this study. Faecal incontinence severity scores represent a more accurate reflection of the patient's incontinence and are more likely to reflect the effects of treatment interventions on incontinence (Abou Khalil and Boutros, 2022).

Staff outcome measures: This was obtained from two surveys (one prior to the intervention and another at the end of the intervention) to assess staff knowledge and confidence in bowel care. Post-intervention interview data was also used to understand the findings.

7.9 Chapter summary

This chapter has demonstrated how the evidence and theory were combined to develop an intervention to address faecal incontinence among older people living with dementia in care homes. The rationale for each intervention component had been explored. How the intervention was delivered had been explained. In the next chapter, how the intervention was delivered through multiple case studies to determine effect of the intervention (with its combined components) on bowel care, and whether the staff who delivered the intervention considered the intervention acceptable is presented.

Chapter 8: Key findings of the ImFaCON feasibility study

This chapter presents findings from the primary research study. The findings are presented in two parts. Part 1 concentrates on residents' outcomes and is presented under two headings: 1) unit level comparisons and 2) multiple case studies. Some of the raw data are presented in Appendix 28. The data used in the feasibility was gathered via the electronic person-centred care software (PCCS). Part 2 presents staff outcomes – knowledge about bowel care and confidence in performing bowel care which was obtained from pretest-posttest questionnaires. The latter part of Chapter 7, as well as those reported below contain the methods of the feasibility study.

8.1 Feasibility study

The National Institute for Health and Care Research (NIHR) (2022) describes feasibility studies as those studies that focus on conducting research to examine whether the studies can be done. Feasibility studies are unlike pilot studies, which are smaller versions of the main study that aim to test whether the components of the main study can work together (Orsmond and Cohn, 2015). This means that feasibility studies are conducted first, followed by pilot studies which examine outcomes of the intervention as would be implemented in a randomised control trial (RCT), but on a smaller scale (National Institute for Health and Care Research (NIHR), 2022, Orsmond and Cohn, 2015). Feasibility studies are iterative, formative, and adaptive (Bowen et al., 2009). Hagen and colleagues (2011) used the term *kinesthetic learning* to describe this developmental learning process.

The reporting of findings of this feasibility study follows the TIDieR (Template for Intervention Description and Replication) guidelines (Hoffmann et al., 2014). The TIDieR checklist is included in Appendix 29. Steps 1 to 10 of the TIDieR checklist are addressed in Chapter 7. Therefore, this chapter presents Steps 11 and 12 of the TIDieR checklists.

8.2 Feasibility study's eligibility criteria

Residents aged 65 years and above living in the care home who have dementia and are faecally incontinent. Further details of residents' selection are provided in Chapter 6. All care staff working in the care home were eligible to participate.

8.3 Setting and recruitment

The setting of this study had previously been reported in Chapter 6. Participants' recruitment for the feasibility study is reported below.

Residents

A total of twenty-one care home residents were initially recruited (10 from Unit-1 and 11 from Unit-2), but one of them from Unit-1 was excluded for being faecally continent. Therefore, baseline characteristics are provided for twenty residents (9 residents from Unit-1, and 11 residents from Unit-2) (Table 8.1). Of the twenty residents, their mean (standard deviation (SD)) age was 90.20 (±7.88), age range 67 to 102 years. The baseline characteristics show that the mean (SD) number of comorbidities among the residents was 8.30 (± 3.13), and the mean (SD) number of medications used by the residents was 8.65 (± 4.07). There were 17 females and 3 males. All the residents had a history of dementia, and all were faecally incontinent, with the mean (SD) faecal incontinence (FI) episodes per unit over last four weeks prior to the intervention being 156.05 (±72.56) (Table 8.1).

Four residents died during the intervention (one resident from Unit-1 and three residents from Unit-2) (Appendix 30). Therefore, the results presented cover the 16 residents (eight residents from each care home unit) that started and completed the research study.

Care staff

A total of sixteen staff members participated in the pre-intervention knowledge and confidence survey, but two staff members did not complete the post-intervention survey because they had moved to a new care home site. For this reason, the results are presented for the remaining fourteen staff members that completed both pre- and post-intervention surveys.

8.4 Data analysis of the feasibility study

The data for this study was analysed using descriptive statistics. This enabled calculation, description, and summary of collected research data in a logical, meaningful and efficient way (Vetter, 2017). A t-test parametric test (Bevans, 2020) was used to compare the means of FI episodes in two care home Units. Results are presented in tables, line graphs boxplots. The boxplot shows the median as a horizontal line inside the box and the interquartile range (range between the 25th to 75th percentiles) as the length of the box. The whiskers (line extending from the top and bottom of the box) represent the minimum and maximum values when they are within 1.5 times the interquartile range from either end of the box (Barton and Peat, 2014). Scores greater than 1.5 times the interquartile range are out of the boxplot and are considered as outliers, and those greater than 3 times the interquartile range are extreme outliers (Ghasemi and Zahediasl, 2012).

Table 8.1: Baseline characteristics of residents recruited to the research study

Study ID	Age	Sex	Medical background	Total number of FI episodes in 4 weeks	Total number of comorbidities	Total number of medications used
FF001	97	F	Registered partially sighted, dry senile macular degeneration, dementia/Alzheimer's disease (atypical or mixed type), atrial fibrillation, bilateral cataracts, sliding hiatus hernia, pernicious anaemia, knee osteoarthritis, gastritis unspecified, vertigo, and hypothyroidism.	122	11	9
FF002	77	F	Urinary tract infection, type 2 diabetes, atrial fibrillation 2014, cardioembolic stroke with right middle cerebral artery infarct and extensive cortical laminar necrosis 2012, coronary artery disease 2009, knee pain 2006, essential hypertension 1998, behavioural problem 2015, sub-acute confusion probably secondary to non-convulsive status epilepticus 2012, dementia, left total kneel replacement 2011, and lumbago 1998.	72	12	20
FF003	88	F	Chronic heart failure, osteoporosis, high blood pressure, hyperthyroidism, chronic kidney disease, depression, dementia, breast cancer, cataract in both eyes, macular degeneration, stroke, spinal stenosis, gout, cellulitis, and deep vein thrombosis.	135	15	15
FF005	99	F	Opioid toxicity, hypoglycaemia, type 2 diabetes, hypertension, liver disfunction, chronic kidney disease, severe cervical myopathy, left ventricular failure, and vascular dementia.	203	9	4
FF006	91	F	Hypercholesterolaemia, degenerative reaction to disc disease, left fracture neck of femur, degenerative arthritis in lumbar spine, mild osteopenia of thoracic spine, chronic renal impairment, impaired glucose tolerance, dementia and associated memory loss, and impaired fasting glycaemia.	290	10	6
FF007	89	F	Alzheimer's disease late onset 2016, arthritis, history of stroke, hypertension, anxiety, and depressive disorder.	173	6	10
FF008	90	M	Essential hypertension, dementia, depression, tissue aortic valve replacement, unpredictable behaviour, and recurrent falls.	164	6	7
FF009	94	F	Alzheimer disease (2009), asthma, hypothyroidism, carcinoma, chronic kidney disease stage 3 without proteinuria, chronic venous insufficiency, leg oedema, bronchitis, non-diabetic hyperglycaemia, severe frailty, and severe constipation, and anaemic.	282	12	11
FF010	86	F	Endoscopic retrograde cholangiopancreatography (ERCP) with sphincterotomy, arthroscopic trimming of lateral meniscus, laparoscopic cholecystectomy, fibrocystic disease of breast, anxiety with depression, breast abscess, prolapsed lumbar intervertebral disc, Hashimoto's disease, and vascular dementia.	147	9	11
GF001	91	F	Vascular dementia, anxiety, depression, hypertension, osteoarthritis, knee replacement (twice), shoulder replacement, and cellulitis of both legs.	160	9	9

GF002	87	M	Congestive heart failure, chronic kidney disease stage 2, bipolar disorder, cataracts, osteoporosis, diabetic foot ulcer, idiopathic peripheral autonomic nephropathy, maniac depressive disorder, dementia, cellulitis both legs, fracture ankles and toes, type 2 diabetes, and gout right hand.	55	13	13
GF003	67	F	Chronic kidney disease stage-3, vascular dementia, pure hypercholesterolaemia, history of acute myocardial infarction, fracture of radius and metatarsal bone, fracture of humerus, and transluminal balloon angioplasty of coronary artery.	43	7	8
GF004	89	F	Advanced dementia, essential hypertension, osteoporosis, and recurrent urinary tract infections.	154	4	6
GF005	96	F	Vascular dementia, chronic kidney disease stage-3, pure hypercholesterolaemia, history of acute myocardial infarction, fracture of radius and metatarsal bone, fracture of humerus, and transluminal balloon angioplasty of coronary artery.	106	7	4
GF006	92	F	Alzheimer's disease, total abdominal hysterectomy, asthma, osteopenia, multiple infarcts, dementia, and adverse reaction to drugs used in musculoskeletal and joint disease.	213	8	10
GF007	94	M	Alzheimer's disease/dementia, chronic back pain, ischemic heart disease, glaucoma, and hypertension.	34	5	8
GF008	102	F	Alzheimer's disease/dementia, deep vein thrombosis, bilateral cataract, osteoarthritis of spine, and deteriorating renal function.	214	5	3
GF009	84	F	Alzheimer's disease/dementia, mammoplasty, and malignant neoplasm of female breast.	126	3	5
GF010	96	F	Alzheimer’s disease, essential hypertension, organic delusional syndrome, type 2 diabetes, cervical spondylosis, osteoarthritis of cervical spine, anxiety, and depression.	226	8	7
GF011	95	F	Dementia, essential hypertension, osteoporosis, and hypothyroidism.	202	4	7

Key: M = Male; F = Female; FF = Care Home Unit-1; GF = Care Home Unit-2

8.5 Data completeness during the intervention

During the intervention period, the staff from Unit-1 engaged much more with the intervention compared with the staff on Unit-2 as evident from completed paper case report forms (CRFs) (as referenced in Chapter 7 – Appendix 24). On Unit-1, the manager placed the study documents (including the CRFs) in communal areas to keep staff reminded about the ongoing study. Whereas the manager on Unit-2 placed the study documents in her office. The CRFs were supposed to be completed by care staff during day shifts that ran from 07:00 to 19:30 daily. During four weeks of the intervention period, none of the CRFs on Unit-2 were completed. It transpired that the manager on Unit-2 had misplaced the study documents one week prior to her contracting Covid-19 and staying at home for convalescence. During this time, Unit-2 was closed to visitors due to Covid-19 restrictions, thus resulting in the PhD candidate consulting with the staff mostly through virtual means (e.g., Zoom and Microsoft teams meetings). The stakeholders' engagement and data completeness are presented in Table 8.2 below. Data completeness was judged as the measure of any data entry per resident per week on the CRF vs no data entry on the CRF.

Table 8.2: Data completeness during ImFaCON intervention

Unit-1						
	Recruitment period		Intervention period			
	1st Week	2nd Week	Week-2	Week-4	Week-6	Week-8
Staff	Started	completed				
Residents	Started	completed				
Paper CRF completion*			70%	80%	60%	90%
Unit-2						
	Recruitment period		Intervention period			
Staff	Started	completed				
Residents	Started	completed				
Paper CRF completion*			20%	0%	0%	30%

*Paper Case Report Form (CRF) completion (measured in percentage) demonstrates care staff engagement during the intervention period.

During the first two weeks, 70% of the CRFs were completed on Unit-1 compared with 20% CRFs completion rate on Unit-2 (Table 8.2). None of the CRFs on Unit-2 were completed at the end of the fourth and sixth weeks of the intervention (Table 8.2). However, there was a 100% completion of the electronic bowel diaries as evident by the PCCS output (Appendix

28). Therefore, due to the incomplete nature of the CRFs, the PCCS data was used for analysis.

8.6 Part-1: Residents' outcome – Unit level comparisons of faecal incontinence

The episodes of faecal incontinence and stool consistency (quantified by Bristol Stool Chart) among residents from two care home units are presented below. All residents were faecally incontinent and never had continent stool episodes; so, bowel frequency recorded in the Person-Centred Software record (described in Chapter 7) and/or CRF represents FI episodes.

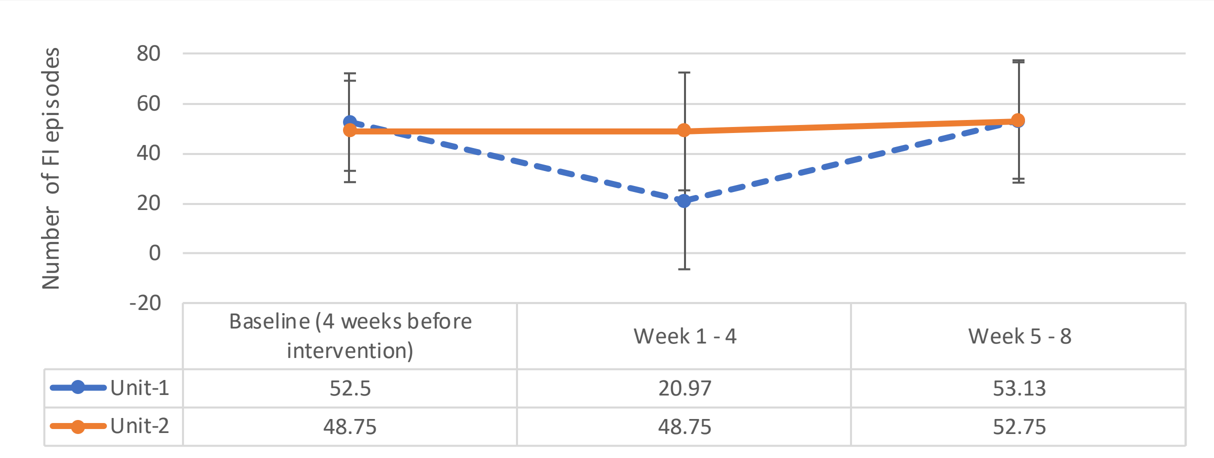
8.6.1 The average faecal incontinence frequency of two units of a care home

There was no overall significant difference in frequency of faecal incontinence (FI) episodes among the care home residents from the two units between baseline (four weeks prior to the intervention) and four weeks leading to the end of the intervention (mean and standard deviation (SD) of FI episodes per unit (8 residents): 50.63 and 52. 94 (p=0.77) (Table 8.3). However, there was a reduction in FI episodes among residents in Unit-1 during the first four weeks of the intervention [mean (SD) FI episodes per unit (8 residents): 20.97 (± 27.45)] compared with Unit-2 [mean (SD) FI episodes: 48.75 (± 23.60)] (Figure 8.1).

The severity of FI episodes among residents of both care home units was measured using an abbreviated St Mark's Incontinence Score (SMIS) (Vaizey et al., 1999). The SMIS was adapted because flatulence was not calculated in line with the operational definition of FI stated in Chapter 1). Therefore, the SMIS for Unit-1 and Unit-2 during the last four weeks of the intervention compared to baseline measures were found to be 10.88 [(SD = ± 1.46), range = 9 to 13] and 10.25 [(SD = ± 2.25), range = 7 to 13] respectively (Appendix 31). This means that the difference in severity of FI episodes between the two Units was 4.87%, which is not clinically useful or significant.

Table 8.3: The mean, standard deviations, and p-value of faecal incontinence frequencies of two care home units (8 residents per unit) from baseline to end of the intervention

t-Test: Two-Sample Assuming Unequal Variances		
	Baseline (4 weeks before intervention)	*From week 5 to week 8 of the intervention*
Mean per Unit	50.62	52.93
Variance	528.25	534.99
Observations	16	16
Hypothesized Mean Difference	0	
df	30	
t Stat	-0.28	
P(T<=t) one-tail	0.38	
t Critical one-tail	1.69	
P(T<=t) two-tail	0.77	
t Critical two-tail	2.04	



	Baseline (4 weeks before intervention)	Week 1 - 4	Week 5 - 8
Unit-1	52.5	20.97	53.13
Unit-2	48.75	48.75	52.75

Figure 8.1: Graph of faecal incontinence frequencies of two units

8.6.2 The distribution of stool consistency per unit of the care home based on number of counts

Unit-1

The distribution of stool consistency count (expressed in mean and standard deviation) on Unit-1 is summarised in Table 8.4 below. Among the eight residents in Unit-1, there was no change in the number of stool with a consistency described as hard stool (Type 1-3) comparing the baseline measures (i.e., four weeks prior to the intervention) [mean (SD): 5.0 (± 2.39)], to the first four weeks of the intervention [mean (SD): 5.25 (± 3.33)], as well as the last four weeks of the intervention (mean: 4.75 ± 4.77) (Table 8.4). The number of normal stool consistency (Type 4 & 5) count reduced throughout the intervention period (Figure 8.2). For loose stool (Type 6 & 7), there was no significant difference between the baseline and first four weeks of the intervention [mean (SD): 18.88 (± 19.54) and 20.75 (± 27.45)]. However, more loose stool was reported from Week-5 to Week-8 of the intervention [mean (SD) of Type 6-7 stool count: 53.13 (± 23.34)] (Figure 8.2).

Table 8.4: Unit-1 number of stool consistency count during the study period, expressed in mean and standard deviation for 8 residents

	Baseline (4 weeks before intervention)	*Week 1 - 4*	*Week 5 - 8*
Types 1-3	5.0 ± 2.39	5.25 ± 3.33	4.75 ± 4.77
Types 4-5	39.75 ± 22.92	27.25 ± 9.79	2.67 ± 2.67
Types 6-7	18.88 ± 19.54	20.75 ± 27.45	53.13 ± 23.34

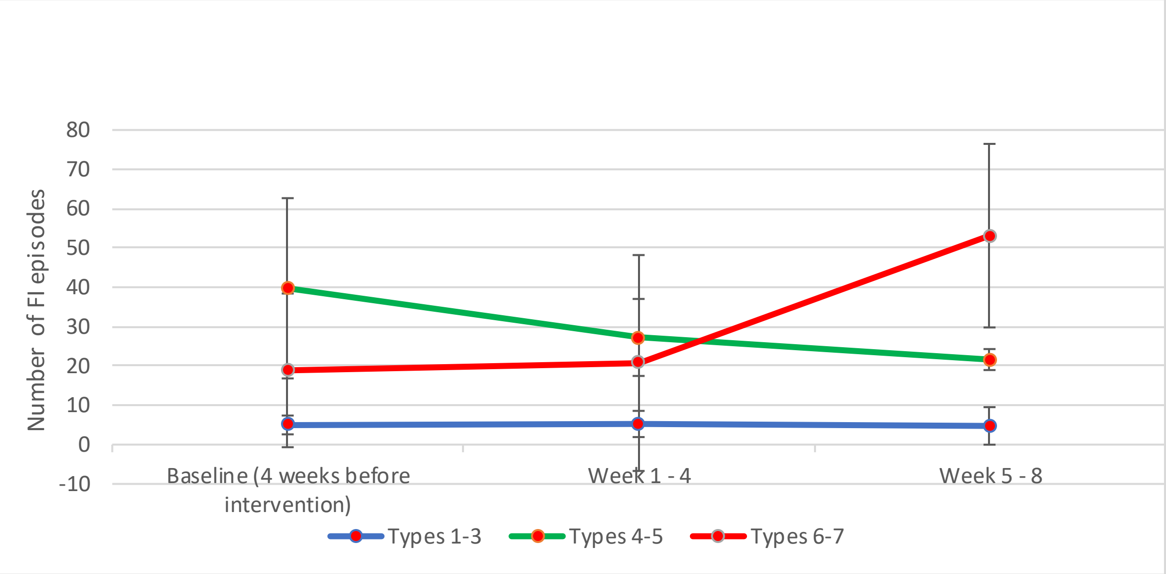


Figure 8.2: Unit-1: The mean (and standard deviation) of stool consistency count per four weeks per unit (8 residents)

Unit-2

The distribution of stool consistency count (expressed in mean and standard deviation) on Unit-2 is summarised in Table 8.5 below. The mean of the number of hard stool (Type 1-3) count among residents in Unit-2 also did not change significantly comparing baseline measures (i.e., four weeks prior to the intervention) [mean (SD) stool consistency count per unit: 4 (± 3.12)] to the first four weeks of the intervention [mean (SD): 5.75 (± 5)] (Table 8.5). However, during the last four week of the intervention (Week-5 to Week-8), the number of Type 1-3 stools reduced [mean (SD): 2 (± 2.14)] (Table 8.5). Similarly, the number of both Type 4 & 5 and Type 6 & 7 stool consistencies did not change significantly from baseline measures (four weeks prior to the intervention) [means (SD): 25 (± 14.97) and 19.75 (±

20.31)] and the first four weeks of interventions [means (SD): 24.13 (± 18.08) and 18.75 (± 23.60) respectively] (Table 8.5). During the last four weeks of the intervention period, both Type 4 & 5 and Type 6 & 7 stool counts increased [means (SD): 37.63 (± 11.81) and 52.75 (± 24.53) respectively]. Among the three stool categories, the counts of Type 6 & 7 category increased during the last four weeks of the intervention period (Figure 8.3).

Table 8.5: Unit-2 number of stool consistency count during the study period, expressed in mean and standard deviation

	Baseline	4th Week	8th Week
Types 1-3	4.0 ± 3.12	5.75 ± 5.0	2.0 ± 2.14
Types 4-5	25.0 ± 14.97	24.13 ± 18.08	37.63 ± 11.81
Types 6-7	19.75 ± 20.31	18.75 ± 23.60	52.75 ± 24.53

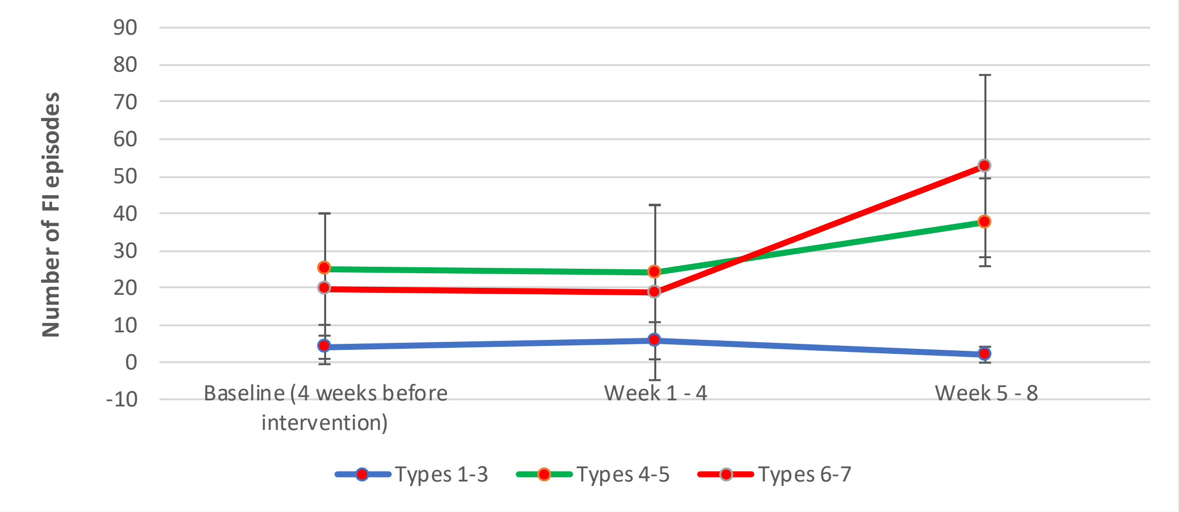
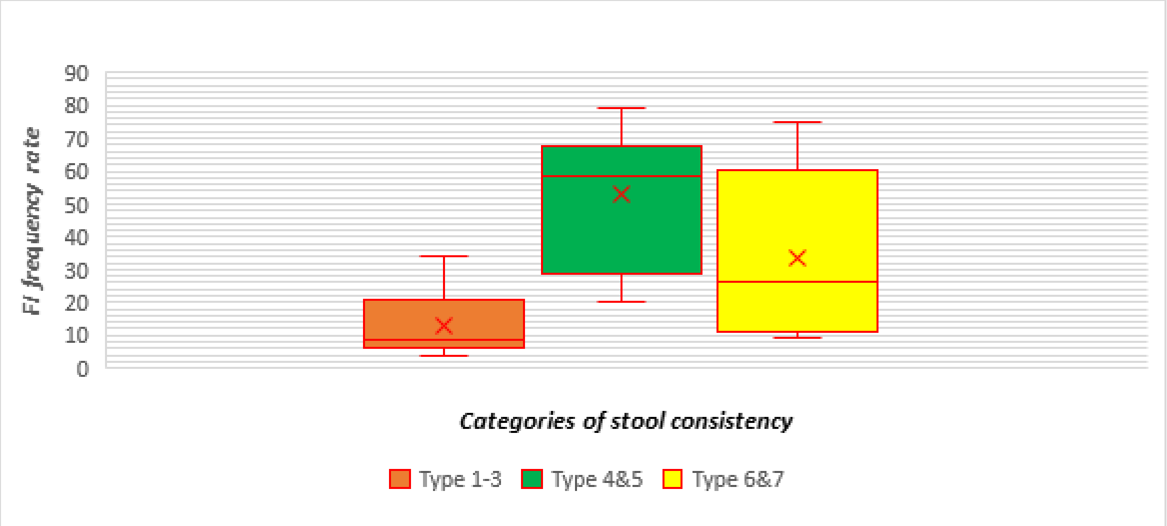


Figure 8.3: Unit-2: The mean (and standard deviation) of stool consistency count per four weeks per unit

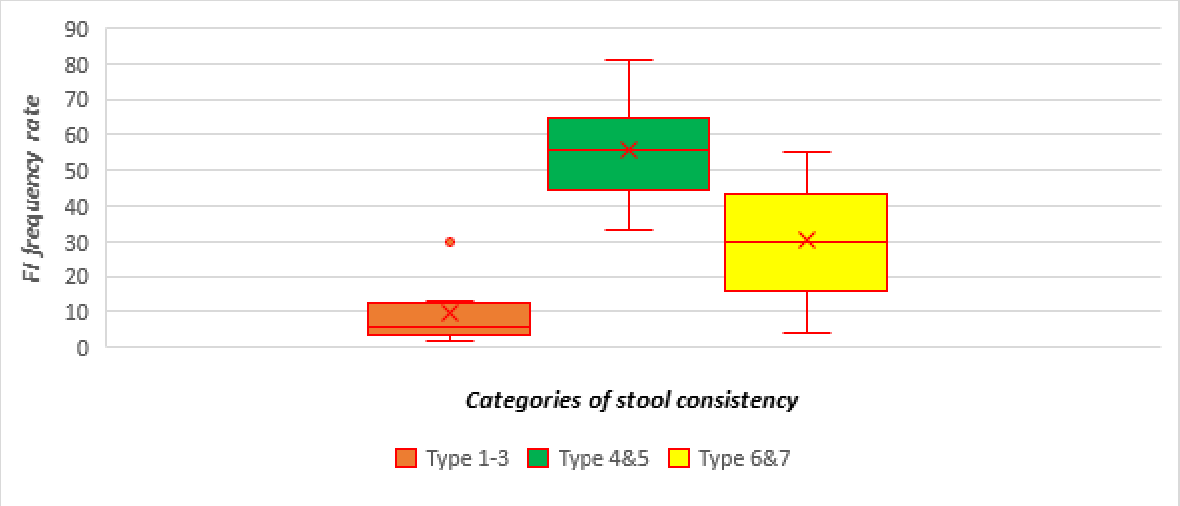
8.6.3 The rate of stool consistency: Unit-1

The median rate of stool consistency of residents on Unit-1 at baseline (four weeks prior to the intervention) for Type 1-3, Type 4 & 5, and Type 6 & 7 categories were 8.50% [interquartile range (IQR) = 8.25%], 58.50% (IQR = 22.25%), and 26.50% (IQR = 31.75%) respectively (Figure 8.4). From Week-5 to Week-8, the same categories of stool consistency were 6% (IQR = 7%), 55.50% (IQR = 14.75%), and 30% (IQR = 20.50%) respectively (Figure 8.5). As can be seen in Figure 5.5, there is an outlier of Type 1-3 stool during the last four weeks of the intervention, which is 30% suggesting that one of the residents had more hard stools than the average residents taking part in the study on Unit-1.



Legend: The X represent the mean of the values, the solid lines through the boxplots represent the medians, and minimum and maximum values of the quartiles are represented by the Whiskers of the boxplots

Figure 8.4: Unit-1 residents' stool consistency (based on Bristol Stool Chart) over four weeks at baseline



Legend: The X represent the mean of the values, the solid lines through the boxplots represent the medians, and minimum and maximum values of the quartiles are represented by the Whiskers of the boxplots

Figure 8.5: Unit-1 residents' stool consistency (based on Bristol Stool Chart) from week 6 to week 8)

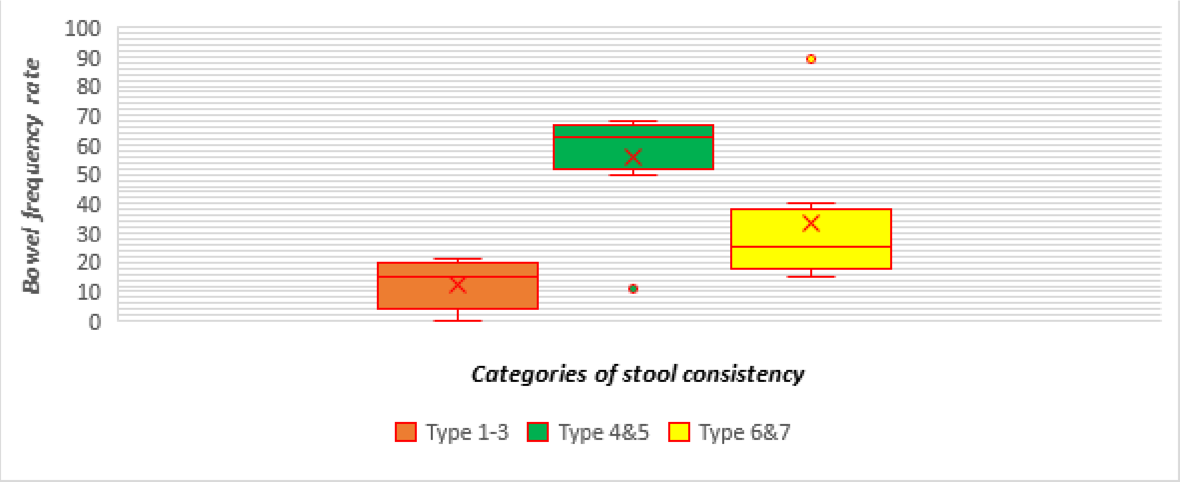
Comparing figures 8.4 and 8.5, it can be observed that at the end of the intervention, the median stool consistencies vary much less (Figure 8.5) compared with the baseline data

(Figure 8.4). However, there is no significant difference in the medians of the stool consistencies from baseline to the end of the intervention (Figures 8.4 and 8.5).

8.6.4 The rate of stool consistency: Unit-2

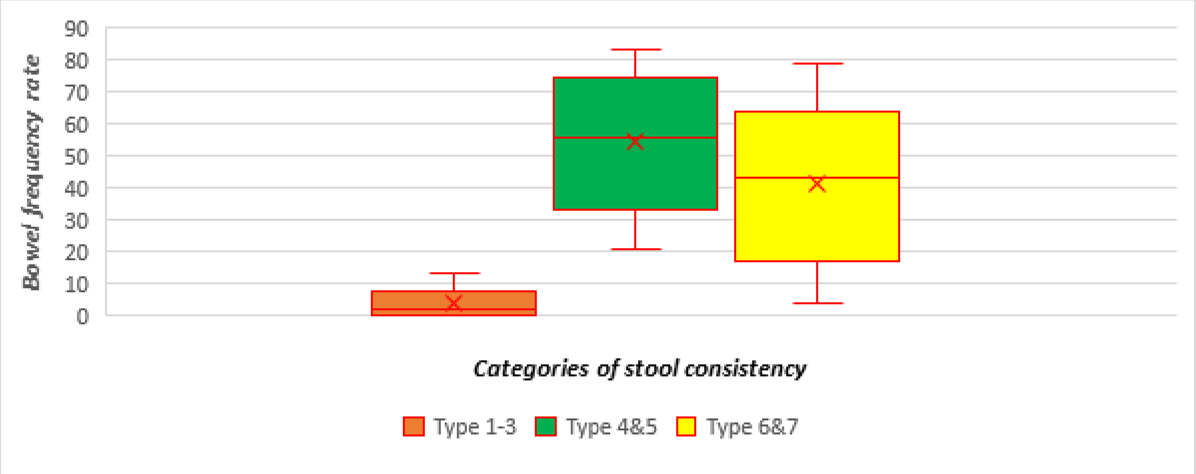
The medians of stool consistency of residents on Unit-2 at baseline for Type 1-3, Type 4 & 5, and Type 6 & 7 categories were 15% [interquartile range (IQR) = 8%], 59% (IQR = 9%), and 28.50% (IQR = 21%) respectively (Figure 8.6). From Week-6 to Week-8, the same categories of stool consistency were 2% (IQR = 4.5%), 55.50% (IQR = 22.50%), and 43% (IQR = 22.25%) respectively (Figure 8.7). In Figure 8.6, there are two mild outliers of Type 4&5 and Type 6&7 stool categories during the first four weeks leading to the intervention, namely 11% and 89%.

Summary of these analysis can be found in Appendix 32.



Legend: The X represent the mean of the values, the solid lines through the boxplots represent the medians, and minimum and maximum values of the quartiles are represented by the Whiskers of the boxplots

Figure 8.6: Unit-2 residents' stool consistency (based on Bristol Stool Chart) over four weeks at baseline



Legend: The X represent the mean of the values, the solid lines through the boxplots represent the medians, and minimum and maximum values of the quartiles are represented by the Whiskers of the boxplots

Figure 8.7: Unit-2 residents' stool consistency (based on Bristol Stool Chart) from week 6 to week 8)

Comparing Figures 8.6 and 8.7, it can be observed that four weeks prior to the intervention, the mean stool consistencies vary much less (Figure 8.6) compared to the four weeks leading to the end of the intervention (Figure 8.7). However, there is no significant difference in the medians of the stool consistencies from baseline to the end of the intervention.

8.7 Summary of findings for resident's outcome

The summary of finding for residents' outcome in this study is presented in Table 8.6 below.

Table 8.6: The summary of findings for the residents' outcome at week-8

	Unit-1	**Unit-2**	**Interpretation**
Mean episodes of FI	M = 50.63	M = 52.94	Some changes, but not statistically significant (P=0.77)
Severity of FI (SMIS)	M = 10.88 (± 1.46) Range = 9 to 13	M = 10.25 (± 2.25) Range = 7 to 13	4.78% difference in severity between units; not clinically significant.
Types 1-3 stool	No change	Number of episodes reduced	No overall improvement
Types 4 & 5 stool	Residents experienced less episodes	Residents experienced more episodes	Inconclusive
Types 6 & 7 stool	Residents experienced more episodes of loose stool	Residents experienced more episodes of loose stool	No overall improvement

Key: M = mean; P = p-value

8.8 Multiple case studies

This section presents findings from the multiple case studies. For each case study, a medical background is presented (previously summarised in Table 8.1), followed by baseline characteristics. The resident's individualised bowel care intervention is then presented. Findings from the intervention which was delivered over eight weeks is finally presented qualitatively, with an overall conclusion. A visual summary of findings from the multiple case studies is provided. Details of the FI episodes and stool consistency described under each case study can be found in Appendix 30.

The intervention was developed to be individualised based on the individual residents' characteristics (Chapter 7). The intervention components were then mapped out through the advice of staff members who had previously worked with the residents and knew the residents' bowel patterns and capabilities (as detailed in Chapter 7). Details of how the intervention was individualised (and reasons for the intervention) is attached (Appendix 33).

8.8.1 *Unit-1 care home residents (age 77-99)*

Resident FF001

Background: A 97-year-old female resident with the background of being registered partially sighted, dry senile macular degeneration, dementia/Alzheimer's disease (atypical or mixed type), atrial fibrillation, bilateral cataracts, sliding hiatus hernia, pernicious anaemia, knee osteoarthritis, gastritis unspecified, vertigo, and hypothyroidism.

Baseline characteristics: Resident doubly incontinent, bedbound, and needs assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 38 episodes per month. Of the total number of FI episodes, 24% of the time it was hard stool (Type 1-3 stool consistency), and 10% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving eleven prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, upper body arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 41 per month, of which hard stool reduced from 24% down to 2%, but loose stool (Type 6 & 7) increased from 10% to 37%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 32, of which 6% was Type 1-3 and 13% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) showed improvement, but the resident experienced looser stool. There was 15.79% reduction in FI episodes.

Resident FF002

Background: A 77-year-old female resident with the background of urinary tract infections, type 2 diabetes, atrial fibrillation 2014, cardioembolic stroke with right middle cerebral artery infarct and extensive cortical laminar necrosis 2012, coronary artery disease 2009, knee pain 2006, essential hypertension 1998, behavioural problem 2015, sub-acute confusion probably secondary to non-convulsive status epilepticus 2012, dementia, left total kneel replacement 2011, and lumbago 1998.

Baseline characteristics: Resident doubly incontinent; need two staff to transfer with steady from bed to chair. Resident need staff assistance with all aspects of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 24 episodes per month. Of the total number of FI episodes, 4% of the time it was hard stool (Type 1-3 stool consistency), and 75% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving twenty prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes, as well as medication review

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 32 per month, of which hard stool category did not change, and the loose stool (Type 6 & 7) increased from 75% to 84%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 36, of which 6% was Type 1-3 and 44% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) became worse by 2% increment, and the loose stool category reduced from 75% to 44%. There was no improvement in overall FI episodes, as the resident experienced 33.33% more FI episodes.

Resident FF003

Background: An 88- year-old female resident with the background of chronic heart failure, osteoporosis, high blood pressure, hyperthyroidism, chronic kidney disease, depression, dementia, breast cancer, cataract in both eyes, macular degeneration, stroke, spinal stenosis, gout, cellulitis, and deep vein thrombosis.

Baseline characteristics: Resident doubly incontinent; uses wheelchair and needs a staff assistance to transfer from bed into the wheelchair. Resident needs staff assistance with toileting, washing, grooming, and dressing. Resident can feed herself with minimal staff support. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 42 episodes per month. Of the total number of FI episodes, 9% of the time it was hard stool (Type 1-3 stool consistency), and 29% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving fifteen prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 49 per month, of which hard stool category (Type 1-3) increased from 9% to 14%, and the loose stool (Type 6 & 7) decreased from 29% to 27%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 41, of which 12% was Type 1-3 and 29% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) became worse by 3% increment, and the loose stool category (Type 6 & 7) showed no change. There was also no significant change in the overall FI episodes (e.g., only 1% reduction in FI episodes from baseline to end of the intervention).

Resident FF005

Background: A 99- year-old female resident with the background of opioid toxicity, hypoglycaemia, type 2 diabetes, hypertension, liver disfunction, chronic kidney disease, severe cervical myopathy, left ventricular failure, and vascular dementia.

Baseline characteristics: Resident doubly incontinent; is bedbound and needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 85 episodes per month. Of the total number of FI episodes, 8% of the time it was hard stool (Type 1-3 stool consistency), and 24% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving six prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 101 per month, of which hard stool category (Type 1-3) did not change (e.g., it remained at 8%), and the loose stool (Type 6 & 7) increased from 24% to 37%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 104, of which 3% was Type 1-3 and 31% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) reduced from 8% to 3%, but the loose stool category (Type 6 & 7) increased from 24% to 31%. There was no improvement in overall FI episodes, as the resident experienced 9% more FI episodes at the end of the intervention compared with her baseline.

Resident FF006

Background: A 91- year-old female resident with the background of hypercholesterolaemia, degenerative reaction to disc disease, left fracture neck of femur, degenerative arthritis in lumbar spine, mild osteopenia of thoracic spine, chronic renal impairment, impaired glucose tolerance, dementia and associated memory loss, and impaired fasting glycaemia.

Baseline characteristics: Resident doubly incontinent; is bedbound and needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 60 episodes per month. Of the total number of FI episodes, 7% of the time it was hard stool (Type 1-3 stool consistency), and 38% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving four prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 73 per month, of which hard stool category (Type 1-3) decreased from 7% to 5%, and the loose stool (Type 6 & 7) increased from 38% to 47%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 66, of which 6% was Type 1-3 and 42% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) did not change significantly (e.g., only 1% change from 7% to 6%), and the loose stool category (Type 6 & 7) became worse by 4% increment. There was no improvement in overall FI episodes, as the resident experienced 18% more FI episodes at the end of the intervention compared with her baseline.

Resident FF007

Background: An 89- year-old female resident with the background Alzheimer's disease late onset 2016, arthritis, history of stroke, hypertension, anxiety, and depressive disorder.

Baseline characteristics: Resident incontinent of faeces; can mobilise with Zimmer frame with the one staff support. Resident needs minimal assistance with toileting, washing and feeding. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 71 episodes per month. Of the total number of FI episodes, 6% of the time it was hard stool (Type 1-3 stool consistency), and 15% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving ten prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Mobilise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 61 per month, of which hard stool category (Type 1-3) minimally increased by 1% (from 6% to 7%), and the loose stool (Type 6 & 7) increased from 15% to 36%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 53, of which 13% was Type 1-3 and 25% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) increased from 6% to 13%, and the loose stool category (Type 6 & 7) increased from 15% to 25%. There was some improvement in the overall FI episodes, which reduced from 71 to 53 episodes per month (e.g., a 25% decrease in FI episodes per month).

Resident FF008

Background: A 90- year-old male resident with the background of essential hypertension, dementia, depression, tissue aortic valve replacement, unpredictable behaviour, and recurrent falls.

Baseline characteristics: Resident doubly incontinent; is bedbound and needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 56 episodes per month. Of the total number of FI episodes, 12% of the time it was hard stool (Type 1-3 stool consistency), and 68% of the time it was loose stool (Type 6 & 7 stool consistency). The resident was receiving seven prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes was 32 per month, of which hard stool category (Type 1-3) increased from 12% to 22%, but the loose stool (Type 6 & 7) decreased from 68% to 56%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 40, of which 2% was Type 1-3 and 55% was Type 6 & 7.

Conclusions: The hard stool category of FI (Type 1-3) decreased from 12% to 2%, and the loose stool category (Type 6 & 7) decreased from 68% to 55%. There was also some improvement in the overall FI episodes, which reduced from 56 to 40 episodes per month (e.g., a 29% decrease in FI episodes per month).

Resident FF010

Background: An 86- year-old female resident with the background of endoscopic retrograde cholangiopancreatography (ERCP) with sphincterotomy, arthroscopic trimming of lateral meniscus, laparoscopic cholecystectomy, fibrocystic disease of breast, anxiety with depression, breast abscess, prolapsed lumbar intervertebral disc, Hashimoto's disease, and vascular dementia.

Baseline characteristics: Resident doubly incontinent; is bedbound and needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 44 episodes per month. Of the total number of FI episodes, 34% of the time it was hard stool (Type 1-3 stool consistency), and 9% of the time it was loose stool (Type 6 & 7). The resident was receiving eleven prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 14 per month, of which hard stool category (Type 1-3) increased from 34% to 71%, and there was no loose

stool (Type 6 & 7) during this period. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 53, of which 30% was Type 1-3, and 8% was loose stool (Type 6 & 7).
Conclusions: The hard stool category of FI (Type 1-3) decreased from 34% to 30%, and the loose stool category (Type 6 & 7) decreased from 9% to 8%. There was no improvement in the overall FI episodes, which increased from 44 to 53 episodes per month (e.g., resident experienced 17% more FI episodes at the end of the intervention compared with her baseline).

8.8.2 *Unit-2 care home residents (age 84-102)*

Resident GF001
Background: A 91--year-old female resident with the background of vascular dementia, anxiety, depression, hypertension, osteoarthritis, knee replacement (twice), shoulder replacement, and cellulitis of both legs.
Baseline characteristics: Resident doubly incontinent, needs two staff to transfer from bed to chair using a steady hoist. Resident needs staff support with all aspects of her activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 55 episodes per month. Of the total number of FI episodes, 6% of the time it was hard stool (Type 1-3 stool consistency), and 27% of the time it was loose stool (Type 6 & 7). The resident was receiving nine prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.
Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.
Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 49 per month, of which hard stool category (Type 1-3) increased from 6% to 12%%, and the loose stool category (Type 6 & 7) increased from 27% to 47%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 55, of which there was no change in the hard stool category (Type 1-3), but the looser stool category (Type 6 & 7) became worse (increase to 45%).
Conclusions: There was no change in the hard stool category of FI (Type 1-3) at the end of the intervention period, but the looser stool category worsened by 40% (i.e., increased from 27% to 45%). There was no change in the overall FI episodes, which remained at 55 FI episodes per month.

Resident GF002
Background: An 87--year-old male resident with the background of congestive heart failure, chronic kidney disease stage 2, bipolar disorder, cataracts, osteoporosis, diabetic foot ulcer, idiopathic peripheral autonomic nephropathy, maniac depressive disorder, dementia, cellulitis both legs, fracture ankles and toes, type 2 diabetes, and gout right hand.
Baseline characteristics: Resident doubly incontinent; uses wheelchair and needs two staff support for transfer from bed to the wheelchair. Resident needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 14 episodes per month. Of the total number of FI episodes, 21% of the time it was hard stool (Type 1-3 stool consistency), and 15% of the time it was loose stool (Type 6 & 7). The resident was receiving eleven prescribed medications, including “Pro-Re-Nata” (as the circumstance arises) laxative to manage constipation.
Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.
Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 7 per month, of which hard stool category (Type 1-3) increased from 21% to 29%, and the looser stool category (Type 6 & 7) increased from 15 % to 57%). During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 20, of which there was no episode of hard stool category (Type 1-3), but the looser category decreased from 57% to 35%.
Conclusions: The hard stool category of FI (Type 1-3) did not change, but the looser stool category (Type 6 & 7) increased from 15% (at baseline) to 35% (at the end of the intervention). There was no

improvement in the overall FI episode because the resident experienced 57% more FI episodes at the end of the intervention compared with his baseline.

Resident GF005

Background: A 96--year-old female resident with the background of Vascular dementia, chronic kidney disease stage-3, pure hypercholesterolaemia, history of acute myocardial infarction, fracture of radius and metatarsal bone, fracture of humerus, and transluminal balloon angioplasty of coronary artery.

Baseline characteristics: Resident doubly incontinent; unable to stand and needs a hoist transfer; needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 45 episodes per month. Of the total number of FI episodes, 16% of the time it was hard stool (Type 1-3 stool consistency), and 16% of the time it was loose stool (Type 6 & 7). The resident was receiving four prescribed medications, with no "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 51 per month, of which hard stool category (Type 1-3) decreased from 16% to 10%, but the loose stool category (Type 6 & 7) increased from 16% to 25%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 59, of which only 1% was a hard stool category (Type 1-3), but Type 6 & 7 category further increased from 25% to 41%.

Conclusions: The hard stool category of FI (Type 1-3) decreased from 16% (at baseline) to 1% (at the end of the intervention), but the loose stool category (Type 6 & 7) increased from 16% (at baseline) to 41% (at the end of the intervention). There was no improvement in the overall FI episodes, which increased from 55 (at baseline) to 59 episodes per month at the end of the intervention.

Resident GF006

Background: A 92--year-old female resident with the background of total abdominal hysterectomy, asthma, osteopenia, multiple infarcts, dementia, and adverse reaction to drugs used in musculoskeletal and joint disease.

Baseline characteristics: Resident doubly incontinent; needs hoist transfer due to contracture. Resident needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 68 episodes per month. Of the total number of FI episodes, 14% of the time it was hard stool (Type 1-3 stool consistency), and 24% of the time it was loose stool (Type 6 & 7). The resident was receiving ten prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 51 per month, of which hard stool category (Type 1-3) decreased from 14% to 10%, and the loose stool category (Type 6 & 7) increased by 1% (24% to 25%). During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 55, of which 9% was Type 1-3, and 13% was loose stool (Type 6 & 7).

Conclusions: No significant change in the hard stool category of FI (Type 1-3), which decreased from 14% (at baseline) to 9% (at the end of the intervention). The loose stool category (Type 6 & 7) decreased from 24% to 13%. There was a slight improvement in the overall FI episodes, which decreased from 68 to 55 episodes per month.

Resident GF007

Background: A 94--year-old male resident with the background of dementia, chronic back pain, ischemic heart disease, glaucoma, and hypertension.

Baseline characteristics: Resident doubly incontinent; is bedbound and needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 12 episodes per month. Of the total number of FI episodes, 17% of the time it was hard stool (Type 1-3 stool consistency), and 33% of the time it was loose stool (Type 6 & 7). The resident was receiving eight prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 32 per month, of which hard stool category (Type 1-3) remained unchanged, but the loose stool (Type 6 & 7) increased from 33% to 81%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 28, of which Type 1-3 remained unchanged, but the loose stool category was 79%.

Conclusions: There was no change in the hard stool category of FI (Type 1-3), but the loose stool category (Type 6 & 7) increased from 33% (at baseline) to 79% (at the end of the intervention). There was no improvement in the overall FI episodes, which increased from 12 to 28 episodes per month (e.g., resident experienced 57% more FI episodes at the end of the intervention compared with his baseline).

Resident GF008

Background: A 102--year-old female resident with the background of dementia, deep vein thrombosis, bilateral cataract, osteoarthritis of spine, and deteriorating renal function.

Baseline characteristics: Resident doubly incontinent; uses wheelchair (cannot use it independently) and needs two staff support to transfer using a hoist. Resident needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 87 episodes per month. Of the total number of FI episodes, there was no episode of hard stool (Type 1-3 stool consistency), but 89% of the time it was loose stool (Type 6 & 7). The resident was receiving three prescribed medications, all of which were laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 56 per month, of which hard stool category (Type 1-3) was 2%, but the loose stool (Type 6 & 7) decreased from 89% to 68%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 66, of which 3% was Type 1-3, and 70% was loose stool (Type 6 & 7).

Conclusions: The hard stool category of FI (Type 1-3) increased by 3% from baseline to the end of the intervention, but the loose stool category (Type 6 & 7) decreased from 89% to 70%. There was improvement in the overall FI episodes, which decreased from 87 to 66 episodes per month.

Resident GF009

Background: An 84--year-old female resident with the background of dementia, mammoplasty, and malignant neoplasm of female breast.

Baseline characteristics: Resident doubly incontinent; uses a specialised chair and is hoist transferred by two staff from bed to chair. Resident needs staff assistance with all aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 36 episodes per month. Of the total number of FI episodes, 21% of the time it was hard stool (Type 1-3 stool consistency), and 22% of the time it was loose stool (Type 6 & 7). The resident was receiving five prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, Upper arm exercise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 41 per month, of which hard stool category (Type 1-3) increased from 21% to 37%, and the loose stool category (Type 6 & 7) decreased from 22% to 17%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 40, of which 13% was Type 1-3, and 4% was loose stool (Type 6 & 7).

Conclusions: The hard stool category of FI (Type 1-3) decreased from 21% to 13%, and the loose stool category (Type 6 & 7) decreased from 22% to 4% (from baseline to the end of the intervention respectively). There was no significant improvement in the overall FI episodes, which decreased from 41 to 40 (from baseline to the end of the intervention).

Resident GF010

Background: A 96--year-old female resident with the background of Alzheimer's disease, essential hypertension, organic delusional syndrome, type 2 diabetes, cervical spondylosis, osteoarthritis of cervical spine, anxiety, and depression.

Baseline characteristics: Resident is sometimes doubly incontinent; can mobilise to toilet using Zimmer frame (resident needs supervision due to high risk of fall). She needs staff assistance with most aspects of activities of daily living. Four weeks prior to intervention, the frequency of faecal incontinence (FI) episodes recorded was 73 episodes per month. Of the total number of FI episodes, 4% of the time it was hard stool (Type 1-3 stool consistency), and 40% of the time it was loose stool (Type 6 & 7). The resident was receiving seven prescribed medications, including "Pro-Re-Nata" (as the circumstance arises) laxative to manage constipation.

Intervention: Scheduled toileting, mobilise 8 times daily, with high fibre snacks and fluid intakes.

Findings: During the first four weeks of the intervention, the frequency of FI episodes recorded was 86 per month, of which hard stool category (Type 1-3) increased from 4% to 8%, but the loose stool (Type 6 & 7) decreased from 40% to 35%. During the last four weeks of the intervention (Week-5 to Week-8), the total FI episodes was 99, of which 3% was Type 1-3, and 45% was loose stool (Type 6 & 7).

Conclusions: There was no significant change in the hard stool category of FI (Type 1-3), which decreased from 4% to 3%, but the loose stool category (Type 6 & 7) increased from 40% to 45%. There was no improvement in the overall FI episodes, which increased from 73 to 99 episodes per month.

8.9 Residents for whom there was overall reduction in frequency of FI episodes

Five residents (three from Unit-1 and two from Unit-2) showed that the overall episodes of FI reduced over the eight weeks intervention period. These residents comprised of four females and one male, with the age range from 89 to 102 years old. Comorbidities among the five residents ranged from 6 to 11, and number of medications taken by the five residents ranged from 3 to 10. All residents, except one, needed assistance in all aspects of their activities of daily livings and all were supposed to receive scheduled toileting and upper arm exercise 8 times daily. The younger of the five residents was mobile (used Zimmer frame to mobilise) and received scheduled toileting with mobility exercise 8 times daily (Table 8.7).

Table 8.7: Residents for whom there was overall reduction in frequency of FI episodes

Resident	Age	Capability in ADLs	Number of Comorbidities	Number of medications taken	Intervention
FF001	97	All care	11	9	ST + Upper arm exercise 8 times daily
FF007	89	Mobile with ZF	6	10	ST + Mobility 8 times daily
FF008	90	All care	6	7	ST + Upper arm exercise 8 times daily
GF006	92	All care	8	10	ST + Upper arm exercise 8 times daily
GF008	102	All care	6	3	ST + Upper arm exercise 8 times daily

Key: All care = means need staff assistance in all activities of daily livings; ST = Scheduled Toileting; ZF = Zimmer frame

8.10 Residents for whom there were either overall increase or no change in frequency of FI episodes

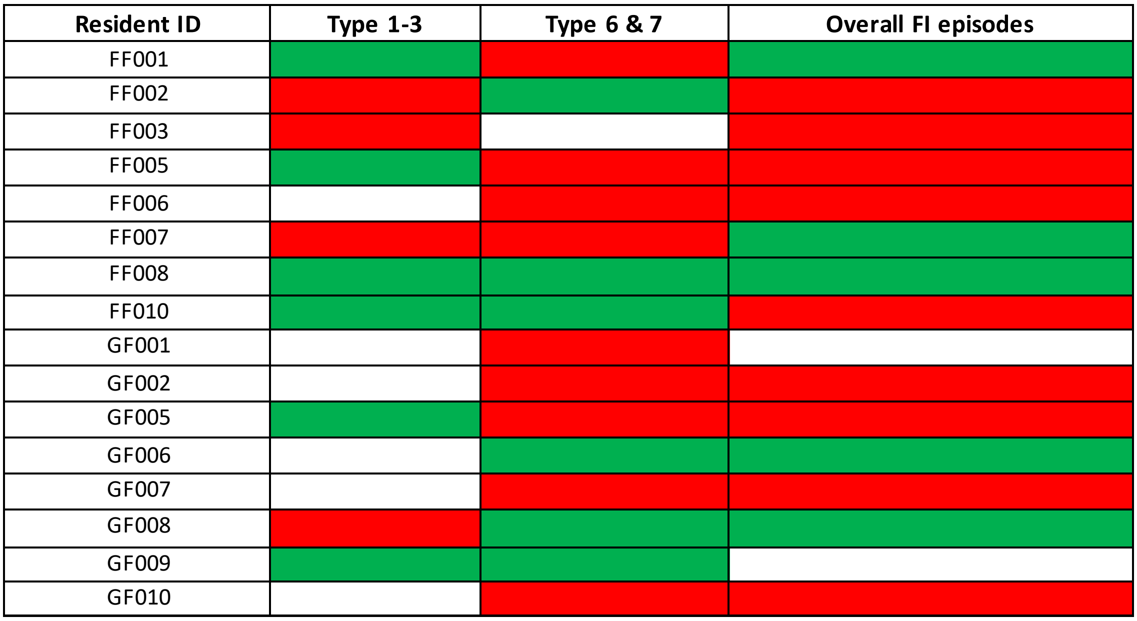
In nine of the residents, the overall frequency of FI episodes increased over the eight weeks intervention period. The nine residents comprised of seven females and two males, with the age range from 77 to 99 years old. In two other residents (both females, aged 84 and 91 years), the overall frequency of FI episodes did not change. Among the residents for whom the overall frequency of FI increased, comorbidities among them ranged from 6 to 15, and the number of medications taken by them ranged from 4 to 20. For the other two residents who showed no change in overall frequency of FI during the intervention period, their underlying comorbidities were 4 and 9, and number of medications taken by them were 5 and 9 respectively (in order of young to old). Among the eleven residents for whom there were either an increase in the overall frequency of FI episodes, or no overall change during the intervention period, all but one needed staff assistance in all aspects of their activities of daily livings; they received scheduled toileting and upper arm exercises 8 times daily. One resident was able to mobilise with staff assistance and received scheduled toileting with mobility exercise 8 times daily (Table 8.8).

Table 8.8: Residents for whom there was overall reduction in frequency of FI episodes

Resident	**Age**	**Capability in ADLs**	**Number of Comorbidity**	**Number of medications taken**	**Intervention**
FF002	77	All care	12	20	ST + Upper arm exercise 8 times daily
FF003	88	All care	15	15	ST + Upper arm exercise 8 times daily
FF005	99	All care	9	4	ST + Upper arm exercise 8 times daily
FF006	91	All care	10	6	ST + Upper arm exercise 8 times daily
FF010	86	All care	9	11	ST + Upper arm exercise 8 times daily
GF001	91	All care	9	9	ST + Upper arm exercise 8 times daily
GF002	87	All care	13	13	ST + Upper arm exercise 8 times daily
GF005	95	All care	7	4	ST + Upper arm exercise 8 times daily
GF007	94	All care	6	8	ST + Upper arm exercise 8 times daily
GF009	84	All care	4	5	ST + Upper arm exercise 8 times daily
GF010	96	Mobile with supervision	8	7	ST + Mobility 8 times daily

Key: All care = means need staff assistance in all activities of daily livings; ST = Scheduled Toileting

For easier reference, a visual summary of the multiple case studies indicating for whom (and for whom not) the intervention appeared to lead to improvement is presented in Figure 8.8 below.



Resident ID	Type 1-3	Type 6 & 7	Overall FI episodes
FF001	🟩	🟥	🟩
FF002	🟥	🟩	🟥
FF003	🟥	⬜	🟥
FF005	🟩	🟥	🟥
FF006	⬜	🟥	🟥
FF007	🟥	🟥	🟩
FF008	🟩	🟩	🟩
FF010	🟩	🟩	🟥
GF001	⬜	🟥	⬜
GF002	⬜	🟥	🟥
GF005	🟩	🟥	🟥
GF006	⬜	🟩	🟩
GF007	⬜	🟥	🟥
GF008	🟥	🟩	🟩
GF009	🟩	🟩	⬜
GF010	⬜	🟥	🟥

Red colour = deterioration; Green colour = improvement; White colour = no change

Figure 8.8: Visual summary of outcomes for stool consistency per individual resident

8.11 Part-2: Care staff outcomes – Knowledge and confidence scale results

Care staff completed questionnaires during the first and last week of the intervention period to assess their knowledge and confidence in bowel care. Fourteen staff completed the pre-and post-intervention questionnaires and the results of their scores are presented in Table 8.9. There was an overall mean increase of 19% bowel care knowledge among care staff (i.e., an increase in mean score from 73% at baseline to 92% post-intervention). Similarly, the average staff confidence score at the end of the intervention was 91%, a 15% improvement from baseline score (mean baseline score = 76%) (Table 8.9).

Table 8.9: pre-and post-intervention scores for bowel care knowledge and staff confidence scales (n = 14)

	Bowel care knowledge			**Confidence performing bowel care**		
Participants	*Pre*	*Post*	*Change*	*Pre*	*Post*	*Change*
1	76%	100%	24%	80%	97%	17%
2	87%	80%	-7%	79%	85%	6%
3	53%	90%	37%	75%	90%	15%
4	68%	100%	32%	74%	90%	16%
5	77%	85%	8%	68%	86%	18%
6	63%	91%	28%	75%	95%	20%
7	89%	95%	6%	90%	100%	10%
8	71%	90%	19%	70%	90%	20%
9	69%	100%	31%	75%	97%	22%
10	91%	97%	6%	90%	95%	5%
11	69%	93%	24%	75%	80%	5%
12	83%	88%	5%	80%	95%	15%
13	73%	88%	15%	75%	85%	10%
14	53%	91%	38%	60%	95%	35%
Mean score	***73%***	***92%***	***19%***	***76%***	***91%***	***15%***

8.12 Discussion

The key findings of this feasibility study are that there were some changes in stool consistency among individual residents. However, the changes did not result in an overall reduction of faecal incontinence episodes in the participating care home units. At individual resident level, there was an overall reduction in episodes of bowel movements among five residents, but these reductions did not manifest in continent episodes. A critical analysis of the outcomes of the feasibility study is discussed below.

In evaluating the findings of the feasibility study, first this section focuses on four of Proctor's health service implementation measurements, namely: feasibility, fidelity, appropriateness (in this case staff knowledge and level of confidence in performing bowel care is used as a proxy), and efficacy (Proctor et al., 2011, Proctor et al., 2009). Secondly, the section discusses the circumstances under which the intervention was delivered and potential reasons why the intervention worked (or failed) in units' comparisons, as well as at individual resident level. The section then outlines the strengths and limitation of the feasibility study and ends with a conclusion.

8.12.1 Implementation measures of the feasibility study

Feasibility is the extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting (Bowen et al., 2009, Karsh, 2004). The concept of feasibility is invoked to explain an initiative's success or failure as reflected in recruitment, retention, or participation rates (Proctor et al., 2011). In the current ImFaCON study, staff recruitment was high because most participants had already been recruited in Phase-1 of the research project (stakeholders' engagement).

Fidelity is the extent to which an intervention is implemented as it was prescribed in the original protocol (Chernick et al., 2021, Rabin et al., 2008). The fidelity of the ImFaCON study was poor due to very poor engagement of the staff from Unit-2 of the care home. Only about a quarter of the paper Case Report Forms (CRFs) were completed by Unit-2 staff, as compared 75% completion rate by Unit-1. The poor fidelity may imply that the intervention was not acceptable to the care staff, thus undermining feasibility of the study.

Appropriateness is the perceived fit, relevance, or compatibility of the innovation or evidence-based practice for a given practice setting, and/or perceived fit of the innovation to address a particular issue or problem (Proctor et al., 2011). Using outcome measures for staff knowledge and confidence in performing bowel care, it can be concluded that the ImFaCON intervention was appropriate for the care home setting because it improved staff knowledge and confidence levels in bowel care.

Efficacy is getting things done; it is the ability to produce a desired amount of the desired effect, or success in achieving a given goal (Burches and Burches, 2020). The ImFaCON intervention aimed to reduce frequency of FI episodes among older people living with dementia in care homes. At a unit level comparison, there was small improvement in reducing overall FI frequency episodes among residents in Unit-1 and no improvement among residents in Unit-2. At individual resident level, some residents responded positively, while for other residents the overall frequency of FI episodes increased. The five residents for whom there were overall episodes of FI reductions in this feasibility study were older, had fewer comorbidities, and were receiving fewer number of medications. This study confirms finding from a previous study carried out in 20 care homes in Norway which found that residents' participation in activities for more than 1/3 of the time was a protective factor for not being incontinent (Blekken et al., 2016). However, it is not known how many times residents participated in activities in this feasibility study. Therefore, it is unknown if the exercise component also played a mediating role in those that showed some improvement. In this study, all the residents were dependent on staff for support with their activities of daily livings and the residents probably participated in a similar exercise regime. It is unknown what exactly residents did because the CRFs were largely incomplete. The potential explanation for the reduction of FI episodes among the five residents is that they had fewer other underlying medical condition and were receiving few numbers of medications.

8.12.2 The circumstances under which the intervention was delivered in the care home

The ImFaCON study was designed through a collaborative work with the care home stakeholders as detailed in Chapters 6 and 7. The intervention development valued the input of the care home staff and took into considerations the residents characteristics and the care home's routine activities. ImFaCON study was delivered in December 2021 and January 2022, just after the second major wave of the Covid-19 pandemic. The unprecedented strain on health and social care systems, particularly the care home sector, caused by the global outbreak of the Covid-19 pandemic cannot be over emphasised.

At the time of the intervention, many of the care home staff who were previously familiar with the study had either moved to a new care home site or had been promoted to senior positions elsewhere within the care home following reorganisation of the care home. The intervention was delivered under two new unit managers, both of whom were not familiar with the study; both managers subsequently learned from PowerPoint presentations delivered both virtually and face-to-face by the PhD candidate. Studies showed that when care homes experience system changes or reorganisation, uptake of new interventions will likely be limited (Boorsma et al., 2011).

The ImFaCON study contained various components with the option to individualise the intervention. The care home staff directed which component was applicable to the residents they thought were more suitable for the study. At the time of the intervention, visitation to the care home was also advised against nationally (except for "essential workers"). The PhD candidate was allowed to visit once a week because he is also a registered nurse. For this reason, the management of the intervention was mostly done virtually (e.g., through regular online meetings with the care home staff). The day to day running of the intervention was carried out by the unit managers. During all the weekly study visits, the unit manager on Unit-1 showed keen interest in the study. Whereas the manager on Unit-2 on two occasions forgot that there was a scheduled visit at all. The lack of CRFs completion (Table 8.2), is evident of lack of Unit-2 staff engagement during the feasibility study.

8.12.3 Potential reasons for outcomes of ImFaCON study

Organisational context is known to impact on the successful implementation of healthcare initiatives in care homes (Bunn et al., 2020). Evidence also suggests that the ways improvements to healthcare for residents in care homes are implemented depends on a range of factors, including institutional and sectoral priorities, leadership styles, communication patterns, staff interest, and the quality of pre-existing relationships between staff and visiting healthcare professionals (British Geriatriacs Society, 2021, Bunn et al., 2020, Peryer et al., 2022). The potential reasons for the outcomes of the ImFaCON study include time constraint and resources needed for study implementation, compatibility of intervention with existing working arrangement of the care home, poor senior staff engagement, and procedural drift (Bunn et al., 2020, Peryer et al., 2022).

Time constraint and resources needed for study implementation: There is plethora of evidence that demonstrate how care home resources, staff capacity and workload are strained (Backman et al., 2021, Bunn et al., 2020, Cousins et al., 2020, Wagg et al., 2022). At the time of the ImFaCON study, the study site seemed overwhelmed with how to tackle the spread of the Covid-19 pandemic amidst staff shortages which the unit managers continually complained about (and was evident by the presence of agency staff). Unfortunately, the timing of the intervention made it impossible for the PhD candidate to contribute any more than what he was allowed to do. The day-to-day running of the intervention (which should have been done by the PhD candidate) was left with the unit managers, who were busy managing their staff. Although the managers assured me that the staff were following the ImFaCON manual, there is no guarantee whether the staff followed the instructions as evident by number of Case Report Forms (CRFs) that were completed. The poor documentation makes it almost impossible to determine how exactly the outcomes were affected by each component of the intervention.

A qualitative systematic review of 33 process evaluations found that when time constraints are experienced by the staff, habitual ways of working take priority over novel research activities (Peryer et al., 2022). This seems to have been the case with the ImFaCON study. The staff seems to have prioritised other care home activities over activities of the intervention. This was evident during the weekly scheduled visits when none of the staff were observed filling out the CRFs in real time. Although, the CRFs were designed to be compatible with the Person-Centred Software used by the care staff to record care activities, the CRFs seemed an extra burden to the staff.

Compatibility of intervention with existing working arrangement of the care home: Research evidence suggests that uptake of research innovation is likely achieved when the intervention is acceptable to healthcare professionals, residents, and staff; when the intervention fits existing care home routines; and when there are opportunities for ongoing consultation with staff (Bunn et al., 2020, Close et al., 2013, Gage et al., 2012). Research has identified practices within the care that works against successful uptake of interventions, among which include a task-focused approach to care, a preoccupation with risk reduction, or staff with a limited skill set working with residents who had advanced dementia (Hall et al., 2009, Kinley et al., 2014, Oye et al., 2016).

Some of these factors equally underpinned the intervention development phases as detailed in Chapters 6 and 7. Although steps were taken to ensure that the intervention fitted within existing care home routines (e.g., allowing the care staff to identify potential residents and to advise on which component could benefit each individual resident), and to encourage uptake of ImFaCON intervention, the efforts did not materialise as was anticipated. Two major factors potentially compounded to the overall lack of staff engagement: first, the intervention was delivered during Covid-19 pandemic and therefore staff were perhaps more preoccupied with the Covid-19 outbreak and other infection control measures; secondly, the first four weeks of the intervention period was in December (i.e., during festive month). It could be that staff were more focused on protecting the residents and themselves from Covid-19 and were looking forward to spending Christmas with their loved ones.

There is also evidence that care home culture negatively affects uptake when the systems of care and required staffing levels are incompatible with those required for a new intervention (Arendts et al., 2018, Mileski et al., 2020). Peryer and colleagues (2022) refer to these issues as organisational slack that include staff availability and capacity expressed as staff workload, staff turnover, and whether an innovation was seen as a priority by the care home. Around the Christmas period (and new year's celebration), there is a general tendency for health and social care services to encounter staff shortages because many regular staff take annual leave. This was also true at the care home when the ImFaCON intervention was carried out.

Poor senior staff engagement: A recent systematic mapping review found that care home leadership can influence the uptake of an innovation (Bunn et al., 2020). Research studies have cited the importance of leadership from care home managers and/or senior direct-care staff (Backman et al., 2021, Bunn et al., 2020), and from staff acting as clinical champions or persuasive leaders (Blekken et al., 2015a, Brodaty et al., 2014, Davison et al., 2013). Research studies investigated leadership issues prospectively through early engagement with care home managers (Boyd et al., 2014, Fossey et al., 2018) and/or the appointment of clinical champions (Blekken et al., 2015c, Surr et al., 2020). For example, in one randomised controlled trial (Livingston et al., 2019), researchers held regular supervision and troubleshooting meetings with care home managers; whereas in different study, other researchers gave champions sustained support and coaching aimed at building their confidence (Ballard et al., 2017). These engagement processes appeared to contribute to sustained delivery of the interventions.

However, there is a documented impact of a lack of leadership on intervention delivery within the care settings, which include managers' resistance to change, delegation of responsibilities to staff without the skill or authority to implement change, turnover of managers, and/or insufficient management attention to the innovation (Bunn et al., 2020). In this feasibility study, the Unit-2 manager showed lack of interest in the study (e.g., misplaced the study documentation, declined to participate in meetings, and delegated study responsibilities to different members of the care staff, often requiring the PhD candidate training the staff on how to conduct the study). The manager's lack of interest probably cascaded down to the junior staff, who also showed low interest in the study.

Procedural drift: Procedural drift (also referred to as practical drift), which has its root in safety science (Bisbey, 2014, Peryer et al., 2022), refers to the human tendency to change, deviate from, or avoid a recommended or required sequence of repeated activities overtime. While some deviations from a prescribed protocol may enhance long-term sustainability of an intervention, others may signify a vulnerability to implementation failure (Peryer et al., 2022). According to Peryer and colleagues (2022), if staff cannot identify meaning behind implementation activities, sustained engagement is unlikely. And when activities diminished, mindfulness, intervention adherence and commitment to the entire implementation process weaken also, thereby leading to inconsistencies in data collection and lack of reliability in findings.

Two weeks leading to the intervention, the care staff seemed more engaging as evident by their contributions towards residents' selection and intervention mapping. However, one week into the intervention, the effect of procedural drift began to manifest though staff lack of engagement (e.g., not completing CRFs). The poor staff engagement may also be attributed to the overwhelming nihilistic belief about managing FI in older people with dementia living in care homes, as was found in Chapter 6. In other words, staff did not probably believe that the intervention could lead to reduction in episodes of FI among the residents, thus impacting on sustained engagement and eventual poor documentation.

Strengths and limitations of the study: Development of the ImFaCON study was guided by the MRC framework for complex interventions (Craig et al., 2008), based on FINCH programme theories (Goodman et al., 2017), as was developed through collaborative work with the care home stakeholders in Chapter 6, and two systematic reviews (Chapters 2 and 3). The testing of realist programme theories to enable intervention development is unusual but the approach has been successfully applied by other researchers of primary care dementia support and other care home studies (Froggatt et al., 2020, Goodman et al., 2017, Griffiths et al., 2022).

In this study, it was not possible to know how long the individual residents have had dementia and/or lived with faecal incontinence because the time of diagnosis of dementia and onset of faecal incontinence were omitted from the Person-centred software that was used to gather residents' medical information. It was not also documented anywhere in nursing notes how individual dementia affected their ability to be continent (e.g., to recognise the urge to defaecate, to communicate their needs to care staff, to their ability to recognise toilet facilities). A potential explanation for this is the lack of consistent approach to how information about care home residents' medical history, care needs, and preferences are collected and used in the UK (Musa et al., 2020, Towers, 2022). There is complete absence of linkage between the UK National Health Service (NHS) and care home data (Musa et al., 2022), like the minimum dataset (MDS) (e.g., the International Resident Assessment Instrument (Inter-RAI)) that exist in other countries such as Canada, New Zealand, parts of Australia, and some countries of mainland Europe (Hutchinson et al., 2010). The need for reliable, routinely collected shared-care data has become both obvious and urgent since the outbreak of the Covid-19 pandemic which disproportionately affected care home residents nationally and internationally (Burton et al., 2021, Department of Health and Social Care, 2022a, Gordon et al., 2020, UK Government, 2022b). Fortunately, the DACHA (Developing resources And minimum dataset for Care Homes' Adoption) study is working with digitally enabled care homes to collect resident level data from care records and match this to data held about them (e.g., in the hospitals and GP data) and the care home in which they live (e.g., Care Quality Commission data) (Towers, 2022, Goodman, 2022).

Notwithstanding the lack of information as mentioned above, steps were taking to mitigate by involving care staff who worked directly with the residents and knew how the dementia affected individual residents. The 'improvement' in five residents may not be directly related to the intervention. The number of residents in the intervention was small and the data quality was poor and possibly unreliable. Nearly as many residents got 'worse' (e.g., experienced more episodes of Types 6 and 7 stool) than better, this may have been all part of the random variation in either data collection or residents' bowel patterns. As it is impossible to tell what the care staff actually did, especially on Unit-2, cause and effect of the intervention cannot be assumed.

Another limitation to the study is that despite the steps taken to codesign the intervention with the aim of components of the intervention being individualised, the cohort of residents on the units made the intervention seem like all residents received the same intervention (e.g., scheduled toileting with upper arm exercise 8 times daily). Only two residents received mobility exercise. This could have been mitigated if care homes were not severely restricted due to Covid-19 restrictions. Additionally, the time constraint on completion of the PhD project could not allow approaching another care homes that have dementia units, as this would have required new application for ethical approval.

8.13 Conclusion

This feasibility study showed that there were some changes in stool consistency among individual residents. However, the changes did not result in an overall reduction of faecal incontinence episodes in the participating care home units. At individual resident level, there was an overall reduction in episodes of bowel movements among five residents, but these reductions did not manifest in continent episodes. The results of pre-and post-intervention questionnaires suggests that the care home staff knowledge about bowel care and confidence in providing bowel care increased.

PART FOUR

Part-4 contains one chapter (Chapter 9), which evaluates the study and provides recommendations for future research and practice.

Chapter 9: Discussion

This chapter presents a summary of the key findings of this PhD research project and key findings in relation to the research questions (Chapters 1, 4, and 6) and the wider relevant literature. Some phases of the project are discussed simultaneously, reflecting the iterative process of intervention development informed by the MRC Framework. As the research questions are intrinsically linked and answered by the same research study, questions relating to the feasibility of the intervention are addressed in Section 9.2.4. The efficacy questions are covered in Section 9.2.5. The chapter then critiques the research study, including strengths and limitations of the theoretical framework and the methods used. The unique and significant contribution of this PhD research to existing knowledge is stated. The implications of the overall findings are discussed in Section 9.5 (Implications for practice) and Section 9.6 (Implications for future research), respectively. The chapter ends by outlining the researcher's reflection and conclusion.

9.1 Summary of key findings

The prevalence review of 12 high-quality studies, 5 medium-quality studies, and 6 low-quality studies (Musa et al. 2019; PhD Paper 1) identified the medians for reported prevalence of isolated faecal incontinence, double incontinence, and all faecal incontinence as 3.5% [interquartile range (IQR) = 2.8%], 47.1% (IQR = 32.1%), and 42.8% (IQR = 21.1%) respectively. The review also found that the most frequently reported correlates of faecal incontinence were cognitive impairment (e.g., dementia), functional incapacity or reduced ability to undertake activities of daily living, urinary incontinence, reduced mobility, advanced age, use of laxatives, and diarrhoea. The findings of this review demonstrate knowledge that was previously poorly understood and confirmed the need for a bowel care intervention to account for modifiable correlates of faecal incontinence, taking into consideration the mediating impact of an individual care home resident's characteristics and the care home environment on continence care.

The Cochrane intervention review of four randomised control trials (Musa et al. [submitted]; PhD Paper 2) found very low certainty of evidence to address whether any of the interventions trialed could reduce frequency or impact of FI episodes among older people living in care homes. None of the studies included in the Cochrane review mentioned how the study was adapted for older people living with dementia. This is also true for the most recent study (Seigneurin-Hérissé et al., 2022) published after the Cochrane intervention review had been submitted for publication. Therefore, the Cochrane intervention review demonstrates knowledge that was previously unknown. Given the high prevalence and burden of FI and dementia in care homes, the complete absence of high-quality evidence on which to base care provided an exigent need for further research.

In evaluating the findings of the feasibility study, four of Proctor's health service implementation measures (Proctor et al., 2011), namely feasibility, appropriateness, fidelity, and efficacy were assessed. There was poor fidelity in the feasibility study, which implies that the intervention was not acceptable. The intervention seems appropriate because it led to increase in staff knowledge and confidence in bowel care. For the efficacy outcomes, the results showed no suggestion of reduction in FI episodes at care home unit levels. However, at individual resident level, five residents with fewer comorbidities who were receiving fewer number of medications showed some reduction in overall frequency of FI episodes.

9.2 Key findings in relation to the PhD research questions and the wider literature

The overall aim of this thesis was to determine whether it was feasible to develop an FI intervention for care home residents aged 65 years and above living with dementia, and whether such intervention could reduce frequency of FI episodes. To address the overarching research question, , a series of research questions were posed as detailed in Chapters 4 and 6. Two systematic reviews, one on the prevalence and correlates of FI (Musa et al. 2019; PhD Paper 1) and the Cochrane intervention review on management of

FI (Musa et al. [submitted]; PhD Paper 2) answered the initial questions about the burden of FI and types of intervention available in practice to manage FI among older people living with dementia in care homes. While the former review established the burden and potential correlates of FI, the latter review found that there was no evidence on which to base an intervention that took account of how dementia impacted on a resident's ability to either initiate appropriate defaecation (i.e., appropriate use of toilet facilities), or engage with continence care when the need arose.

Therefore, the thesis set out to test (and possibly refine) the FINCH programme theories (Goodman et al., 2017), and to develop a complex intervention for the management of FI in older people living with dementia in care homes, and to test the feasibility and potential efficacy of the intervention. The FINCH programme theories derived from a comprehensive realist synthesis (or review) of what continence care works for older people living with dementia in care homes and under what circumstances (Goodman et al., 2017). The FINCH programme theories were tested through stakeholders' engagement (Chapter 6). The stakeholders' engagement fostered deeper understanding of the programme theories, thus enabling development of the feasibility study that was both theory-driven and context dependent. The intervention development and feasibility phases employed in this thesis were guided by the second version of the MRC Framework for complex interventions (Craig et al., 2008).

The feasibility study of the thesis found that there was overall a small reduction of FI episodes among five residents who had fewer comorbidities and were receiving fewer medications. Fidelity to the feasibility study was poor due to several reasons outlined in Chapter 8, including poor engagement of managers and the timing of the intervention (e.g., during the Covid-19 pandemic when most health and social care resources were directed toward infection control measures).

9.2.1 Which potentially modifiable factors are associated with faecal incontinence in older people living in care homes?

The research question concerning modifiable risk factors of faecal incontinence (FI) in older people living in care homes was answered by a systematic review assessing the prevalence, incidence, and correlates of FI (Musa et al. 2019; PhD Paper 1). Findings from the systematic review helped decisions about underlying risk factors that are potentially amendable through care staff intervention, thus fulfilling Step-1 of the development phase (identifying the evidence base) of the MRC Framework (Craig et al., 2008). The review found correlates of FI including impairment in activities of daily living, reduced mobility, urinary incontinence, overuse of laxatives, and problems with stool consistency such as constipation and diarrhoea as potentially amendable to intervention.

9.2.2 Which available interventions for managing faecal incontinence have been identified and previously tested in older people living in care homes?

The research question on evidence-based management of FI in older people living in care homes was answered by a Cochrane intervention review (Musa et al. [submitted]; PhD Paper 2). Setting out to identify the evidence-based on management of FI, the systematic review of available interventions for the management of FI, which included four randomised controlled trials, found no good evidence on which to base an intervention. The complete absence of evidence-based intervention in this context underscored exigent need to develop a new intervention. Findings from the Cochrane intervention fulfilled Step 1 of the intervention development phase of the MRC Framework (Craig et al., 2008).

9.2.3 *What contextual factors are relevant when developing an intervention for the management of FI among older people living with dementia in care homes?*

The research question was answered by utilising available FINCH programme theories from a previous realist review (Goodman et al., 2017). The FINCH review recognised that continence care is part of the everyday work of the care home and articulates the need to incorporate principles of person-centred care with the specifics of taking someone with dementia to the toilet or washing them after FI (Goodman et al., 2017). The FINCH review postulated that clinicians' involvement was key in bowel assessment because the care staff do not have the mandate or permission to carry out invasive assessments such as digital rectal examinations (e.g., to diagnose constipation), and that only when the education, training, facilitation, and positive feedback that care staff receive lead to the staff valuing their personal care work with people living with dementia, and having the skills to tailor practice, will continence care improve. The review argued that these contexts can combine to create a conviction in care staff that they are 'doing the right thing' in persevering with regular toileting and an ongoing assessment and review of what is likely to support the reduction and management of FI (Goodman et al., 2017).

The programme theories were tested through stakeholders' engagement (Chapter 6), thus fulfilling Step 1 of the intervention development phase (identifying and developing theory) of the MRC Framework (Craig et al., 2008). The involvement of the stakeholders, most especially those with dementia, during the intervention development of theory-driven complex interventions have mainly focused on experiences of people with dementia involved in research (Waite et al., 2019), or evaluation protocols (Harding et al., 2018, van den Kieboom et al., 2019). Few papers have reported on the process of involving people with dementia in intervention development (Griffiths et al., 2022). The lack of studies explaining in detail what methods are required to involve people living with dementia in intervention development remains the case (Tolson and Schofield, 2012). Therefore, involving a diverse group of stakeholders in this study attempted to ensure that the intervention was "done with" rather than "done about" the participants. It ensured that the intervention was context dependent and relevant to the stakeholders. These steps established methodological rigour of the intervention.

Testing the FINCH programme theories, the stakeholders' engagement found evidence to support Programme Theories 1, 3 and 6, but less evidence to support Programme Theories 2, 4 and 5 as detailed in Chapter 6. The new insights into the FINCH programme theories include the need to recognise and value the contributions made by care staff who spend more time with the residents and are familiar with the residents' care, including their bowel movement patterns. This is consistent with previous study results which have shown that care staff feel that their skills and commitment were rarely acknowledged and that their work was largely undervalued (Barbosa et al., 2017, Peryer et al., 2022). While the FINCH programme theories suggest a need for bowel care training, the realist evaluation found that the content of such training remains unknown. New insights into the FINCH programme theories also revealed that incorporating person-centred care into the care home routines is difficult, and so too is the involvement of some relatives into the care of the residents. There was an overall nihilistic belief among the care staff that it was not possible to reduce episodes of FI among residents living with dementia in care homes.

The findings from the two systematic reviews (Musa et al. 2019; PhD Paper 1 and Musa et al [submitted] PhD Paper 2) and the findings from the stakeholders' engagement on theory testing (Chapter 6) enabled modelling of a bowel care intervention for older people with dementia living in care homes (Chapter 7). Modelling an intervention in this way helped to fulfil Step 1 of the intervention development (identifying and modelling) of the MRC Framework (Craig et al., 2008).

9.2.4 What is the feasibility of an intervention for the management of faecal incontinence in older people with dementia living in care homes?

The research question was answered by the feasibility study, delivered as pre-and post-intervention data collection, and multiple case studies (Chapter 8). Implementing the feasibility study fulfilled Step 2 of the intervention development (testing intervention procedures and estimating recruitment and retention) of the MRC Framework (Craig et al., 2008). The main objectives of feasibility studies focuses on (a) evaluation of recruitment capability and resulting sample characteristics, (b) evaluation and refinement of data collection procedures and outcome measures, (c) evaluation of the acceptability and suitability of the intervention and study procedures, (d) evaluation of the resources and ability to manage and implement the study and intervention, and (e) preliminary evaluation of participant responses to intervention (Orsmond and Cohn, 2015).

During the Phase-1 study (the realist evaluation to test FINCH programme theories – Chapter 6) participant recruitment was poor. Only two relatives agreed to participate in interviews for the stakeholders' engagement despite 10 invitation letters sent by a Unit Manager on behalf of the PhD candidate, followed by 6 days of lunch time visits (within two weeks) to engage with relatives who had received the invitation. There was also very poor recruitment of residents because the study was carried out on dementia care units and most of the residents on the units were considered by the care home staff to be incapable of engaging in interviews. This ultimately resulted in only one resident participating at the time. Staff recruitment during the stakeholders' engagement resulted in participation of 19/260 staff employed by the care home. The care staff recruited were those who worked on dementia care units (Chapter 6).

During the Phase-2 study (feasibility study – Chapter 8), recruitment (both residents and staff) was high. Residents were identified by care home Unit Managers and consent was sought through consultees. All permanent care staff working on the two dementia care units were enrolled into the study. Notwithstanding, data collection procedures during the feasibility study were poor as outlined in Chapter 8, sections 8.11.1 to 8.11.3. The pre- and post-intervention questionnaires completed by the care staff to test their knowledge and confidence in performing bowel care showed that staff knowledge and confidence levels increased, thus suggesting that the intervention was appropriate.

The ability to manage implementation of the feasibility study was severely impacted by national measures to contain Covid-19, as most staff consultations were done virtually through Zoom or Microsoft Teams meetings. This impacted the ability to evaluate the study procedures. The outcome of this feasibility study resonates with a study carried out in the UK, a staff-led programme about healthy adjustment for people with dementia following care home placement (Hayward et al., 2020). Care home staff used the planner and workbook templates to record which activities had been completed including observable resident responses to undertake activities and resident perspectives on living in the home. The lead researcher was available for telephone support throughout the programme and contacted the care home weekly to check progress and assist. Although most experts deemed the intervention to be well structured, comprehensive, and appropriate, the study is reported as not feasible due to a lack of staff time and dependency on families for some components (Hayward et al., 2020).

Nevertheless, several studies carried out in the care home settings have been found to be feasible (Froggatt et al., 2020, Kaasalainen et al., 2020, Ouden et al., 2019, Siddiqi et al., 2011). Among the studies found to be feasible, the studies have been carried out by research staff (Froggatt et al., 2020, Kaasalainen et al., 2020, Ouden et al., 2019) or a combination of research staff and a care home reference group (Siddiqi et al., 2011). There is also evidence that an intervention fell apart when the support of research staff who collected data on urinary and faecal incontinence was withdrawn (Schnelle et al., 2010).

Taking all the above factors into consideration, it may be said that the ImFaCON study was not feasible at this particular time and care home due to the circumstances under which the study was delivered. Whether it could have failed regardless of the prevailing conditions at the time requires further research.

9.2.5 What are the estimates of efficacy of an intervention for the management of older people with dementia living in care homes?

Efficacy criteria were measured both at individual residents' level and at care home unit level. At individual care home residents' level, only 5/16 resident showed overall small improvement in FI episodes; 11/16 residents showed no change in episodes of FI. At the unit level, there was no overall significant change in frequency of FI episodes among the care home residents comparing both units. Using the St Mark's incontinence score (Vaizey et al., 1999), there was also no significant change in the severity of FI episodes among the residents of both units. Surprisingly, residents from both units experienced more episodes of loose stool at the end of the intervention period. A possible explanation for this is that the care home staff may have prioritised dealing with constipation, a major concern expressed by staff during the realist evaluation (Chapter 6). There is plethora of evidence that suggests that overuse of laxatives in managing constipation can lead to an undesired outcome such as laxative induced diarrhoea (Burton and Mortimore, 2022, Jamshed et al., 2011, Pont et al., 2019). Unfortunately, due to poor staff engagement as reflected in poor documentation, building a pattern of which component of the intervention worked for a particular resident was impossible.

9.3 Critique of the PhD research project

This PhD research project was undertaken to fill the gap in the literature regarding the complete absence of evidence-based intervention that take account of how the residents' individual characteristics such as dementia, as well as the care home environment, may impact on continence care. One of the strengths of this PhD research project is how evidence from different sources were collated to develop a theory-driven, context-dependent intervention. This is the first intervention in continence care for older people living with dementia in care home that considered how dementia and the care home environment may impact how the care staff prioritise and deliver continence care.

This PhD research project is unique in that it employed some of the best-known research approaches into a single research project. For example, the prevalence review used the Joanna Briggs Institute (JBI) critical appraisal checklists to appraise methodological quality of studies included in the review (PhD Paper 1). The JBI is an independent, international, not-for-profit researching and development organisation based in the Faculty of Health and Medical Sciences at the University of Adelaide, South Australia. It develops many critical appraisal checklists involving the feasibility, appropriateness, meaningfulness, and effectiveness of healthcare interventions (Ma et al., 2020). The JBI is one of the reputable organisations for contributing to evidence-base practice (Zeng et al., 2015). As at the time of submitting this thesis, the prevalence review has received 30 citations, thus indicating that the review has reached a wide audience.

Next, the intervention review was carried out as part of Cochrane Intervention Reviews. The protocol of the review (PhD Paper 2) was written and published in Cochrane Database (Musa et al., 2018), and the full review has been submitted for publication. The Cochrane Collaboration, named after the father of evidence-based medicine, Archibald Cochrane (Stavrou et al., 2014), is considered as the best evidence source in health care as detailed in Chapter 3. It must be acknowledged that the Cochrane systematic review process is rigorous and time consuming.

The PhD project adopted principles of realist evaluation based on awareness of research waste and implementation failures that are believed to derive from how research interventions are developed. Developing an intervention collaboratively with stakeholders is advised to avoid research waste and/or research implementation failures as detailed in Chapter 4. The realist research approaches embrace collaborative work with the stakeholders. These approaches enabled building upon programme theories from a comprehensive FINCH review (Goodman et al., 2017) to develop an intervention which not only addressed the research question based on the literature, but also taking into consideration care staff expertise in terms of what intervention component works and for which resident (Chapter 6).

During the feasibility study, the care home staff selected residents based on their knowledge of the residents. Despite these cautious decisions and steps taken to ensure that the intervention resonated with the needs of the residents and that it fitted within the existing care home's everyday routines, poor fidelity to the intervention means that the context in which intervention was delivered did not support its implementation (Chapter 8).

9.3.1 Critiques of the theoretical framework

The concept of 'intervention' is particularly important for nurses, for whom clinical practice encompasses planning, implementing and evaluating interventions consisting of several activities (Bulechek and McCloskey, 1995, Bluecheck et al., 2013). This statement is supported by the European Academy of Nursing Science (EANS) (2022), which goes further to state that nursing is a complex activity and that the study of complex interventions should be a priority for nursing research. Therefore, as a nurse researcher aiming to carry out a research study as part of my PhD required understanding of which theoretical frameworks have been utilised by researchers, particularly in nursing. A comprehensive search for evidence found two systematic reviews on the use of the MRC framework for developing complex interventions (Corry et al., 2013, Levati et al., 2016).

The systematic review by Corry and colleagues (2013) examined the most comprehensive approach to developing complex interventions for nursing research and practice and found that the only guideline reported to have been used in the development of interventions was the MRC framework. Of the 14 papers included in the review, the authors reported that 9 of the papers described the development of an intervention reporting the use of the MRC framework (Corry et al., 2013). In a scoping review that investigated the available evidence relating to the strategies and methods used to optimise complex interventions at the pre-trial stage, the authors identified 17 papers (out of 27 of their included papers) which referred to the MRC framework (Levati et al., 2016). Seven of the papers identified by Levati and colleagues (2016) overlapped the previous review conducted by Corry and colleagues (2013). Each of the studies that referred to the MRC framework used either the first version of the framework (Campbell et al., 2000), or the second version of the framework (Craig et al., 2008).

The use of the MRC framework as the preferred choice for developing and evaluating complex interventions in healthcare has been confirmed by academic literature during this PhD (O'Cathain et al., 2019, Pinto et al., 2021). The PhD candidate is also aware that the second version of the MRC framework has been revised (Skivington et al., 2021). However, it must be acknowledged that the second version of the MRC framework underpinned the methodology of this thesis.

There are a number of strengths of the use of the MRC framework (Craig et al., 2008) to guide the development of the PhD intervention. Among these are the use of the development phase of the MRC framework in identifying the determinants, barriers, and mechanisms that would foster feasibility, adoption, and fidelity in advance of studying the efficacy of the intervention. The use of the MRC framework supported the grounding of the intervention development process using realist programme theories (Fletcher et al., 2016). A more reflective and critical approach to intervention development was demonstrated throughout by explaining the decision-making process in each phase (Craig and Petticrew, 2013).

Limitations of applying the MRC framework in this thesis mainly related to it being time consuming and difficulties inherent in its applicability (Pinto et al., 2021). While there is guidance to apply the MRC framework when developing complex interventions (Bleijenberg et al., 2018, Craig et al., 2013, Fletcher et al., 2016, O'Cathain et al., 2019, Shahsavari et al., 2020), a step-by-step guide of how to achieve this in practice is rare

(Hurley et al., 2016). The lack of clarity on the methods to apply to each phase of the MRC framework presented difficulties and required time to make a fully informed decision on which methods (why to apply the method and how) during the intervention development phase in this thesis.

9.3.2 Critique of the FINCH programme theories

Dementia is an independent risk factor for FI (Bharucha et al., 2022, Musa et al., 2019). The rate of a first diagnosis of FI was found to be threefold higher in people with dementia than in those without dementia (Cole and Drennan, 2019, Grant et al., 2013b). Approximately 80% of residents in care homes have dementia or memory problems (Harrington et al., 2015, Rodriguez et al., 2007). However, there are few intervention studies and little conclusive evidence on what is effective management of FI in people resident in care homes (PhD paper 2). The absence of such evidence in the literature led to the FINCH review authors to include a wider literature (e.g., around bathing) and the significance of care home routines on uptake of interventions, and how living with dementia reframes how everyday clinical problems and activities are addressed (Buswell et al., 2017, Goodman et al., 2017). In other words, the FINCH programmes were extrapolated from a wider literature to speculate what influences, supports, and/or inhibits practices that can promote better reduction and management of FI in people living with dementia in care homes, as discussed in Chapter 5. The FINCH review concluded that there was a need for further research to determine how different care routines and practices could be aligned with interventions to enhance continence care for this subgroup of the population (Buswell et al., 2017, Goodman et al., 2017).

Despite the indirect nature of evidence of the FINCH programme theories, the FINCH review is a comprehensive synthesis of not just evidence from published and unpublished literature, but also from five stakeholders' group discussions. The stakeholders that were consulted during the FINCH review comprised care home managers, care home staff, service user representatives, practice educators, academics, clinicians (e.g., doctors, nurses, and allied health professionals) with specialist interest in FI, continence specialists, and commissioners and providers of continence services (n = 44) (see Chapter 5 of this thesis). The strength of the FINCH programme theories is further embedded in the realist philosophy (see Chapter 4). One of the tenants of realism is that intervention is context-dependent; and that an intervention that works in one context may not always work in other contexts (Greenhalgh and Manzano, 2021, Pawson and Tilley, 1997).

The application of a realist paradigm to research is now widely acknowledged (Devi et al., 2021, Maidment et al., 2020, Marchal et al., 2012, Punton et al., 2020, Roodbari et al., 2021). In this PhD research project, the application of realist evaluation principles (Pawson and Tilley, 1997, Pawson and Tilley, 2004) to test the FINCH programme theories enabled a theory-driven intervention development; it also ensured that the intervention was context-dependent. Nevertheless, as the realist methodology is relatively new, grappling with the realist concepts and how realist approaches are applied in research is challenging and time consuming. Moreover, making a distinction between what constitutes context and mechanism remains a contested debate in the literature (Astbury, 2013, Dalkin et al., 2015, Greenhalgh and Manzano, 2021). These challenges were addressed through external training in realist methodology, feedback from my three supervisors (two of whom have expertise in realist synthesis and realist evaluation) and subscribing to a realist Jisc Mail.

9.3.3 Critique of the methods

The systematic reviews (Chapters 2 and 3) identified modifiable risk factors of faecal incontinence, and that there was no good evidence to base an intervention for older people living in care homes with dementia. Carrying out the systematic reviews was considered appropriate because the reviews enabled collection of all available empirical evidence (Salandra et al., 2021, Shuster, 2011) to explore the prevalence, correlates, and available intervention for treating or managing faecal incontinence. Although 73.9% of the included studies in the systematic review (PhD Paper 1, Chapter 2) were either high or medium quality, no studies were excluded based on quality. Similarly, the intervention review (PhD Paper 2, Chapter 3) included only four randomised controlled trials, none of which contained evidence on which to base an intervention. Nonetheless, systematic reviews are generally the best form of evidence, hence are positioned at the top the hierarchy of evidence (Gopalakrishnan and Ganeshkumar, 2013, Pollock and Berge, 2018).

Following the two systematic reviews mentioned above, it was still unclear which intervention could reduce FI among older people living with dementia in care homes. Fortunately, there already existed the FINCH programme theories (Goodman et al., 2017), which derived from a comprehensive realist synthesis on what works to reduce episodes of FI among older people living with dementia in care homes. A realist synthesis focuses on understanding and unpacking the mechanisms by which an intervention works (or fails to work), thereby providing an explanation, as opposed to a judgment about how it works (Pawson et al., 2005, Rycroft-Malone et al., 2012). The FINCH programme theories, however, derived from a wider literature – not necessarily on care home literature about reducing FI. Therefore, it was imperative to test the theories in practice to determine whether there was evidence before developing an intervention.

The FINCH theories were tested using realist evaluation approaches. The realist approach is fundamentally concerned with theory development and refinement (Pawson, 1996), accounting for context as well as outcomes in the process of systematically and transparently synthesizing relevant evidence (Rycroft-Malone et al., 2012). Given the complex, multifaceted nature of care homes (Bunn et al., 2020, Peryer et al., 2022), and the correlates of FI (Musa et al., 2019), the use of realist approaches not only gave deeper understand of the FINCH programme theories, but also helped to make the intervention more relevant by taking into consideration the individual care home resident characteristics, as well as the everyday routine activities in the care home. This is the first bowel care intervention that has applied realist approaches to intervention development as recommended by Fletcher and colleagues (2016).

The use of quasi-experimental pretest-posttest design during the feasibility study was considered appropriate because it allowed immediate assessment of the intervention. This is important in a care home setting where most residents' life expectancy ranges between 12 to 30 months (Forder and Fernandez, 2011, ONS, 2021), with a high staff turnover (Boorsma et al., 2011). The pretest-posttest design allowed directionality of the research study. In other words, it enabled comparison of baseline measures before the intervention was delivered with the same set of measures at the end of the study to determine efficacy of the intervention.

However, it must be acknowledged that quasi-experimental pretest-posttest designs lack internal validity (e.g., outcome causality cannot be determined, rather associations between intervention and outcomes are made) (Stratton, 2019). In this PhD research, it may be argued that the 'improvement' in five residents was not directly related to the intervention. The number of residents in the intervention was small and the data quality was poor and possibly unreliable. Nearly as many residents got 'worse' (e.g., experienced more episodes of Types 6 and 7 stool) as better, this may have all been part of the random variation in either data collection or residents' bowel patterns.

This PhD research employed a holistic case study methodology because it recognises the inseparable interrelationship between the case and its contexts (Yazan, 2015). This methodology was beneficial for helping to provide explanatory accounts of the intervention delivery, and to understand what happened during study implementation (Beyer and Wright, 2013, Swanborn, 2010) within the care home setting. The case study methodology was compatible with the chosen ontological and epistemological realists' approaches (Easton, 2010) adapted in the PhD study. This PhD research employed multiple case studies because they offer robust analytical conclusions and increase external validity and are generally preferred over single-case study (Yin, 2003, Yin, 2014). However, building case studies can potentially be time-consuming.

9.4 Unique and significant contribution to methodology and knowledge

This PhD project present unique and significant contributions to both methodology and knowledge, which will be set out in turn below.

9.4.1 Unique and significant contributions to methodology

The unique and significant contributions this study has made to methodology are outlined below:

1. This research is the first to utilise realist approaches to theory and intervention development to explore what works and under what circumstance to reduce FI in older people living with dementia in care homes. Previous research (as well as a study published recently) has used experimental designs (e.g., randomised controlled trials) (Blekken et al., 2015a, Booth et al., 2013, Schnelle et al., 2002, Schnelle et al., 2010, Seigneurin-Hérissé et al., 2022), or pretest-posttest design (Chen et al., 2020). Using realist approaches in this PhD research enabled consideration of contextual factors (e.g., residents' characteristics such as dementia, and the care home routinised work). This was identified as a gap in knowledge by the FINCH review (Goodman et al., 2017) and this PhD research goes some way to filling this gap.

2. This research is the first known study which focused on reducing FI in older people living with dementia in care homes. Previous research in FI has neither focused, nor accounted for how dementia impacts on the person's ability to recognise and use toilet facilities within the care home setting. A recent study carried out in France included only dependent residents with no further clarification for reasons for the residents' dependence (Seigneurin-Hérissé et al., 2022).

3. This is the first known study to utilise multiple case studies methodology to explore how an FI intervention impacted had on individual care home residents living with dementia.

4. Furthermore, this is the first known study on FI carried out within the care home setting that presents perspectives of diverse participants concurrently, including residents, family members, care home staff (e.g., care assistants, managers, physiotherapists, dieticians, and pharmacists), and a former geriatrician. Previous studies have focused on one participant group (e.g., either care staff, or residents).

5. By including care home stakeholders' in intervention development and implementation, this PhD research has in some way fulfilled the gaps in the literature identified by the FINCH review (Goodman et al., 2017) regarding studies 'doing intervention with' rather than 'doing intervention to' participants. It ensured that the intervention was relevant to the stakeholders.

9.4.2 Unique and significant contributions to knowledge

The unique and significant contributions this study has made to knowledge are outlined below:

1. This research confirmed, rather than developed, the FINCH review findings on how to support people with dementia. Considering the FINCH review was carried out five years ago, this suggests that researchers are still not engaging with how dementia affects continence related behaviours (e.g., ability to recognise or find toilet and/or recognise the urge to defaecate).

2. This research revealed the need to recognise and value the contributions made by junior care staff who spend more time with the residents and are familiar with the residents' care, including their bowel movement patterns.

3. The research found the need for bowel care training, but the content of such training remains unclear. Therefore, there is a need for further research to determine what bowel care training may empower the care staff, especially when

providing continence care for residents with dementia. This may involve input from dementia care specialists and continence care specialists.

4. Findings from this research suggests that the care staff understand how to manage constipation, but there are inherent difficulties regarding dietary modification within the care home setting because some residents may have other comorbidities.

5. This research has provided new insight about the inherent difficulties around incorporating person-centred care into care home routines for older people living with dementia. This finding adds to existing understanding of personhood and continence care for people living with dementia (Baillie and Gallagher, 2011, Ostaszkiewicz, 2018, Ostaszkiewicz et al., 2020, Ostaszkiewicz et al., 2016b). The twin assaults of experiencing dementia and FI and the challenges inherent in continence care provided for people experiencing both conditions is described by Boddington and Featherstone (2018) as the ‘canary in the coal mine’.

6. This research found nihilistic belief among the care home staff that it was not possible to reduce episodes of FI among residents living with dementia in care homes. This finding is interesting because despite continence being a key moment of care that can reflect the wider care of people with dementia, the care staff do not believe an intervention can make a difference in reducing FI episodes. As the care staff spend more time with residents and are likely familiar with the residents’ bowel movement pattern, it may indeed be true that no intervention may reduce FI episodes among this subgroup of the population. However, research on nihilism in this context is required.

9.5 Implications for practice

The findings of this PhD project have several implications for practice:

1. Organisational context such as the care home environment is known to impact on the successful implementation of healthcare initiatives (Bunn et al., 2020). In practice, unless regulatory bodies such as the Care Quality Commission (CQC) legitimises measures to reduce FI (e.g., make FI as a safeguarding issue such as has been done with falls and pressure ulcers), or the care staff believe that incontinence among older people living with dementia can be ameliorated by intervention, the management of faecal incontinence among this subgroup of the population is likely to remain as reactive measures by the care staff. Contextual factors such as financial incentives for GPs to work with care home staff in identifying residents' bowel problems or sanctions on care homes for not prioritising faecal incontinence are recommended (Goodman et al., 2016). Using CMO configuration to illustrate this: the presence of funding (combined with organisational endorsement) (C) could trigger a commitment and willingness for GPs to work proactively with care home staff to find ways to provide a package of care that supports residents and care staff (M), thus enabling residents to have access to specialist services (O).

2. There is no shortage of data about care home residents held by the NHS and social care or completed by care homes themselves. However, it is not held in one place, is inaccessible to those who need it, and without the data being linked, the care home population is largely invisible to researchers, policy makers and commissioners (Hanratty et al., 2020). Therefore, there is an urgent need for national government in the UK to commit to ensuring that there is a mandated, minimum care home data that is collected and linked with the aim of improving the quality of care received by residents. This may include implementing recommendations of the DACHA study (Goodman, 2022) when shown to be relevant. Such measures have been taken in other countries such as the USA

where the minimum dataset (MDS) for care homes exists (Saliba and Buchanan, 2012), and there is a federally mandated public reporting for care homes (Tamara Konetzka et al., 2021, Werner et al., 2011).

3. There is a need for access to dementia specialists and continence specialists for older people with dementia living in care homes. For this context, mechanisms are the range of resources and skills care staff require to anticipate and respond to the signs and symptoms of dementia; the outcome may be where people living with dementia have behaviours that staff and other residents find ‘challenging’, their care can be managed within the care home.

4. More needs to be done to enable care staff to develop their expertise and not treat the work as predictable routines and/or all about constipation.

9.6 Implications for research

The findings of this PhD project have several implications for research involving intervention development:

1. Care homes are complex adaptive systems of interconnected sub-systems where people, tasks, the physical environment and organisational cultural interact (Moore et al., 2015, Penney et al., 2018). Researchers planning and undertaking research with care homes need a sensitive appreciation of the complex care home context. There is a need for researchers to be aware of routinised work in the care home because care home staff responses to this work have a mediating effect on successful implementation of an intervention (Peryer et al., 2022). In other words, any new intervention must be compatible with existing work routines of the care home as proposed by the FINCH review (Goodman et al., 2017).

2. Research in care home needs to be influenced by the care home managers who run the day-to-day activities of the care home, or risk implementation failure. This

PhD project and evidence from empirical studies suggest that care home leadership can influence the uptake of a given innovation (Bunn et al., 2020). Therefore, without continual managerial and staff support within the care home it is difficult to maintain constructive research-focused discussion and engage in effective problem resolution (Peryer et al., 2022). More importantly, the involvement of care home staff in the intervention development and delivery is important to encourage fidelity.

3. Avoiding procedural drift – if the purpose and objectives of the research are not continually reaffirmed by the leadership of the care home, novel intervention activities may likely be avoided, forgotten, or practised less frequently. This may lead to negative consequences of non-compliance with protocol and fidelity overall (Peryer et al., 2022). Therefore, future intervention development and implementation should consider onsite champions because there is evidence that champion model has proven to improve uptake of interventions in care homes (Bassim et al., 2008, Hall et al., 2021, Lee and Scott, 2009, Ouslander, 2007).

4. There should exist a virtuous learning circle between the researcher and the care home staff who are implementing change as the way to produce a robust and evidence-based intervention. The care staff involvement in implementing the intervention should not be a passive delivery conduit (Peryer et al., 2022). Involving care home staff in intervention development and delivery is important to encourage fidelity. However, this study has shown that this may be not sufficient to override the challenges of the intensive, demanding daily care delivery where there are shortages of staff.

5. The existing workload of care staff before a novel intervention is introduced may contribute to care home divergence from intended implementation strategies. This contextual factor may pose significant limitations on adopting new practices

and sustaining adherence to a protocol that requires specific actions (e.g., timing of data collection) (Peryer et al., 2022). This PhD research project was delivered during theCovid-19 pandemic. Findings from studies show that there is need for more time to embed a new intervention into the daily care home routines (Law and Ashworth, 2022, Damery et al., 2021, Eagar et al., 2020) and to support care home staff to see how they can alter their routines to increase fidelity.

6. Researchers should develop strategies to encourage care staff to develop tolerance within the care team regarding “challenging behaviour” (Richter et al., 2022).

9.7 Plans for the future

Following submission of this thesis incorporating publications, additional publications stemming from this thesis will be completed. These include findings from the realist evaluation and feasibility study respectively. Furthermore, while carrying out this PhD research project, I had the opportunity to work as a Research Fellow on a £2.2 million NIHR funded DACHA (Developing resources and minimum data set for care home adoption) project where I successfully led the realist synthesis of evidence (Musa et al., 2022). Working on the DACHA research project allowed me to work with a larger care home research team that was not part of my PhD. This demonstrates my interest in older people care and my desire to pursue further work on the dual sword – incontinence and dementia – among older people.

9.8 Reflection

Reflection in healthcare practice is defined as the process of reviewing, analysing, and evaluating experiences, drawing upon theoretical concepts or previous learning, to inform future actions (Reid, 1993). Reflective practice has achieved wide take-up in several healthcare fields (Mamede et al., 2020, Mamede et al., 2008, Mantzourani et al., 2019, Owen and Stupans, 2009), and most prominently in nursing (Bulman and Schutz, 2013, Freshwater et al., 2008, Walker et al., 2020, Walker, 1996). Reflection is an essential feature of professional development (Nursing and Midwifery Council (NMC), 2015, Royal College of Nursing (RCN), 2022). Development occurs when things can be said to have improved (Bulman and Schutz, 2013, Mamede et al., 2020). Development is intimately bound with thinking; thinking about the way things are now and thinking about the way things might be improved. To engage in thinking about things in this way is to engage in reflection (Walker et al., 2020, Walker, 1996). The principles of refection were applied throughout this PhD and in the process of writing this chapter. These personal experiences are outlined below. The encounters expressed are presented in linear fashion for coherence.

9.8.1 Description of events before and during the PhD studies

While conducting clinical trials as a Research Nurse across four busy hospitals, I envisioned undertaking a doctoral study to contribute more to my field. At the start of my PhD journey, I read extensively around my topic area (Chapter 1). I discovered that the evidence-based information that was available on the burden of my topic of interest (faecal incontinence among older people living in care homes) was sparse, or non-existent. I also discovered information on evidence-based intervention for reducing episodes of FI in people living with dementia in care homes was lacking in the literature (Chapter 1). Then I planned to undertake two systematic reviews – one to determine the prevalence and correlates of faecal incontinence and to determine the evidence-base intervention to manage faecal incontinence in the care home settings. But there was a problem – I was inexperienced and needed appropriate training.

I discovered that care homes were not usual places to conduct research studies (Chapter 1). I travelled to Trondheim, Norway with my PhD primary supervisor to learn from the experience of researchers that had previously carried out similar research (Blekken et al., 2015a). The original idea for my PhD research project was to replicate a Norwegian study in the UK context. Unfortunately, the Norwegian study in question was reported as inconclusive because it did not result in reduction of faecal incontinence episodes. Back in the UK, I began to think differently on other ways to answer my PhD research questions. I looked at intervention development frameworks and the framework that seemed widely recommended was the MRC Framework on developing complex interventions (Corry et al., 2013, Levati et al., 2016). I needed to fully grasp the concepts proposed by the MRC Framework.

While exploring the MRC Framework on complex intervention studies, it became clearer to me that I needed to consult with care home stakeholders to confirm and/or refine the programme theories that inspired my current PhD supervisors to advertise the studentship that got me on board. To engage in programme theory testing or refinement required understanding of realist evaluation. But there was one big problem – I needed an understanding of realist research methodology.

9.8.2 So, how did I resolve the problems?

Prior to commencing my PhD, I undertook an undergraduate degree in Adult Nursing and an MPH in public health. I worked across four hospitals as a Band 6 Research Nurse, carrying out clinical trials. To give myself an opportunity of pursuing a PhD, I began thinking outside the box from asking consultants at the various hospitals where I worked, to looking for PhD studentships that aligned with my career goals – public health. I began my search from basic google search to findphd.com. Then I was shortlisted for interviews at two prestigious universities, with the interviews scheduled a week apart. I was accepted on a fully funded PhD at King's College London, funded by the Abbeyfield Foundation, and I could not be any happier.

I undertook two systematic reviews to address the gaps in the literature (PhD Paper-1 and PhD Pater 2). For PhD Paper-1, I collaborated with experts from the UK and Norway in the fields of continence, older people, care home, and dementia research. The internal feedback I received from the review team and the guidance by my PhD supervisory team, as well as the external feedback I received from a peer-reviewed journal, aided me to better understand the nature of academic work and to benchmark the quality of my work against what is expected of me in my discipline. For PhD Paper-2, my primary supervisor put me in contact with the Cochrane Incontinence Group and I was registered as a Cochrane Reviews author/editor. I undertook four days of Cochrane Intervention Review methodology in Oxford, UK. Publishing the protocol of PhD Paper-2 through the Cochrane database (with the full review being submitted) fostered my sense of achievement during my PhD studies.

To address my concern about doing empirical research in the care home setting, I undertook voluntary work at the care home that had shown interest in my research topic. The rationale was to familiarise myself with the care home culture and to build-up rapport with the care staff. Research evidence has consistently shown that care home staff are unlikely to engage in research activities because they see it as extra workload (Peryer et al., 2022).

Looking for alternate ways to answer my PhD research questions brought me to choose the MRC Framework on complex intervention. To understand more about the MRC Framework, I joined the European Academy of Nursing Science (EANS). EANS is an independently organised body (funded by research councils from eight different European countries) composed of individual members who have made significant contributions to the advancement of nursing science in Europe through scholarship and research. It is leading the drive to refocus nursing research activity and to develop knowledge for nursing that is both useful and transferrable into practice (European Academy of Nursing Science (EANS), 2022). Thus, members of EANS meet each year for at least a week of Summer School in one of the European countries to teach PhD nursing students from across Europe mixed methods research using the MRC framework on complex interventions. I benefited from EANS scholarship for three years during which I attended Summer Schools in Malmo (Sweden), Ghent (Belgium), and Lisbon (Portugal).

In the quest for an evidence-based, theory-driven intervention I attended a week-long workshop in Realist Methodology Training in Liverpool, run the Centre for Advancement in Realist Evaluation and Synthesis (CARES). Taking part in this training allowed me to develop an awareness of realism as a research methodology and helped to foster delivery of the realist evaluation in this thesis (Chapter 6). It is possible that the training provided by CARES may have helped me in obtaining a Part-time employment as a Research Fellow, where I successfully led the realist synthesis as part of a bigger National Institute for Health and Care Research (NIHR) funded research (Musa et al., 2022).

9.9 Conclusions

This PhD research study has shown that although there were some changes in stool consistency among individual residents, the changes did not result in an overall reduction of faecal incontinence episodes in the participating care home units. At individual resident levels, five residents showed some reduction in episodes of FI, but still had FI episodes. However, even among those residents that showed some overall reduction in episodes of faecal incontinence, the residents experienced more Types 6 and 7 stool (loose stool) at the end of the intervention period compared with the baseline measures. Unfortunately, poor documentation by the care staff who implemented the intervention precluded analysis of effect of individual components of the intervention. It was also not possible to determine what mechanism caused the unintended loose stool in residents at the end of the intervention period. In practice, unless there exists a national mandate for routinely collected care home data, a linkage between care home data and the National Health Services and regulatory bodies such as the Care Quality Commission (CQC), and that the CQC require measures to reduce faecal incontinence (and as making it a safeguarding issue such as implemented for falls and pressure areas), or the care staff understand that incontinence can be ameliorated by intervention through training, the management of faecal incontinence is likely to remain as reactive measures by the care staff. Research in this context needs to value the work provided by junior staff (e.g., Care

Assistants) and be influenced by the care home managers who run the day-to-day activities of the care home, or risk implementation failure.

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APPENDICES

Appendix 1: PhD Paper 1 Supplementary Table S1

Summary of included studies

Study	***Population***	***Definition and data sources***	***Prevalence/incidence of FI/DI***	***Correlates of FI/DI***	***Methodological Quality of study***
Aslan et al. 2009; Turkey; Cross-sectional	N=694residents, aged > 60 years from 5 selected NHs; 56.5% women	FI not defined. DI defined UI and FI which occur together. The authors interviewed residents and also used the MMT to assess mental and functional states.	FI was 10.5% among the residents. Data extracted from Table 5 shows that FI was more common among females (55%) compared to males (18%). However, the authors reported 14% and 6% FI incidence for female and males respectively between January to March 2000.	The factors associated with FI among males according to multivariable logistic regression included diabetes mellitus (RR=57.69; 95% CI: 1.58-2108.23), frequency of FI (RR=32.51; 95% CI: 1.81-583.54), functional incapacity (RR=147.25; 95% CI: 6.23-3478.06) and UI (RR=26.85; 95% CI: 1.73-416.57); whereas, for females associated factors according to multivariable logistic regression included history of stroke (RR=7.01; 95% CI: 1.51-32.63) and functional status (RR=17.35; 95% CI: 5.23-57.48).	**MEDIUM**
Blekken et al. 2016; Norway; Cross-sectional	N=261 residents, from 20 NH units across 10 different NHs; Aged = > 60 years; 66.3% women	FI defined as involuntary loss of liquid or solid stool. Data sources: Norwegian version of interRAI LTCF, (Section H3) and a Norwegian version of St Mark's FI score	Prevalence of FI from interRAL LTCF was 42.1%; from St Mark's FI score it was 54%	Significant predictors of FI (multivariable logistic regression): UI (OR=2.24; 95% CI: 1.56-3.20) , ADL impairment (OR=1.12; 95% CI: 1.05-1.19), Cognitive impairment (OR=1.96; 95% CI: 1.16-2.44), diarrhoea (OR=8.90; 95% CI: 1.87-42.5), paraplegia (OR=4.41; 95% CI: 1.17-16.69), and use of micro-enemas (OR=3.17; 95% CI: 1.83-5.50). Non-statistically significant factors: advanced age, length of NH stay, social engagement, inability to defer defecation for 15 minutes, inability to communicate, depression, and diabetes. Protective factors were average time involved in activities (OR=0.33; 95% CI: 0.10-0.92) and instability in health (OR=0.62; 95% CI: 0.39-0.98).	**HIGH**

Bliss et al. 2013; USA; Cross-sectional	N=111,140 residents, aged ≥ 65 years (mean age = 82 years), admitted to 457 NHs over three years: 2000 to 2002; 65.3% women	No clear definition of FI/DI, except that the authors categorised incontinence data into six variables: Only FI, Only UI, DI, any incontinence, any FI, and any UI. The authors used MDS version 2 and US 2000 census records.	DI was highest (46% in Asians, 44% in Blacks, 36% Hispanics, 27% American Indians and 27% in Whites) and FI only (no UI) was lowest (14% in Blacks, 13% in Hispanics, 10% in American Indians, 9% in Asians and 9% in Whites).	No correlations reported.	**HIGH**
Bliss et al. 2017; USA; Longitudinal cohort	N=39, 181 older NH residents, aged ≥ 65 (mean age = 81.3; SD = 7.6) admitted to 445 NHs in 27 states without DI; 69.2% women	DI was defined as the report of both urinary and faecal incontinence. Data sources: three national data files were analysed - MDS record, OSCAR, and the 2000 US Census.	Of the 39,181 admissions, 24.6% developed DI. Of these, 4% were admitted with isolated FI, and 35.5% with isolated UI; after admission, 19% developed DI at 3 months (90 days); 28% developed DI at 6 months (180 days); 42% developed DI at 1 year; and 61% developed DI at 2 years.	Significant predictors for developing DI over time derived from Cox proportional hazard regression were: UI (HR=1.3; 95% CI: 1.2-1.4), greater severity of cognitive impairment (HR=1.2; 95% CI: 1.16-1.19), more comorbidities (HR=1.1; 95% CI: 1.06-1.09), older age (HR=1.0; 95% CI: 1.0-1.01), greater limitations in ADLs, and lesser quality of nursing home care. Not statistically significantly association with race.	**HIGH**
Burgio et al. 1988; USA; Cross-sectional	N=154 patients from one urban nursing home; mean age = 74 (SD=13.4); 69% women.	FI/DI not defined; No specific tool for measuring FI/DI.	126 (82%) of residents were incontinent of bowel or bladder at least once per day. Of these, 4 **(3%)** displayed FI only and 94 (75%) displayed DI "at least once per week". Characteristics of sample: Cognitive impairment (58%), mobility impairment (95%) and depression (39%).	No correlations reported.	**LOW**
Capewell et al. 1986; UK; Survey	N=400 residents, aged ≥ 64 (age range: 64 to 101, mean age = 80 years). Most of the NH residents (92%) were women.	FI/DI not defined.	All FI among the residents was 26%. This included FI once per week or less and frequent FI. The characteristics of the residents were: feeding dependency (18%), dressing dependency (71%), and cognitive impairment (72%).	No correlations reported.	MEDIUM

Carryer et al. 2017; New Zealand; Cross-sectional	N=276 residents, aged ≥ 65 (mean age = 87.2, with SD=7.4) from 13 NH facilities; More than 70% women (no exact figure given)	FI was defined as involuntary loss of the bowels 3-4 times a month; DI was defined as involuntary loss of urine and faeces. Data source: National Prevalence Measurement of Care Problems questionnaire.	Prevalence of isolated FI was 26.4% and DI was 23.2%. Thus, all FI was 49.6%.	No correlations reported.	HIGH
Chassagne et al. 1999; France; Cohort	N=1186 continent residents, aged > 60 years from 13 French institutions (5 nonmedical NHs and 8 long-term care geriatric facilities).	FI was defined as at least one involuntary loss of faeces. FI categorised as "Transient" or "long-lasting". The authors extracted data from medical records.	New FI occurred in 20% of residents (n=234). Of those who developed FI, 16% (34/234) died during the study, compared with 6.7% (64/952) of those who were continent. Long-lasting or permanent FI was associated with increased mortality.	Factors that were statistically significantly associated with FI from the multivariable analysis were: UI (RR=2.0; 95% CI: 1.50-2.60), presence of neurological disease (RR=1.9; 95% CI: 1.0-3.4), decreased mobility (RR=1.8; 95% CI: 1.1-3.0), severe cognitive impairment (RR=1.4; 95% CI: 1.1-1.9), age older than 70 years (RR=1.7; 95% CI: 1.0-2.8), and acute diarrhoea or faecal impaction. Non-significant factors: age > 80 years, gender, medication use, or history of psychiatric disorder. A protective factor was long stay in a NH for at least 5 years (RR=0.6; 95% CI: 0.4-0.8).	MEDIUM
Chiang et al. 2000; USA; Retrospective chart review	N=413 NH residents from 3 states. Mean age = 84 years; 75% women.	FI not clearly defined, except that FI meant incontinent of faeces only, DI meant incontinent of both faeces and urine, and UI meant incontinent of urine only. Data collected from the MDS, chart documentations.	Isolated FI = 6%; DI = 54%.	Residents with DI were significantly more likely to have cognitive impairment and reduced mobility (i.e., in-bed and transfer from bed-to-chair) compared to continent residents or residents with UI. Number of diagnoses, congestive heart failure, hypertension, diabetes, Parkinson's disease, anxiety, and cancer did not vary with continence status of residents.	HIGH
Harrington et al. 2008; USA; Cross sectional	There were 1,526,066 nursing facility beds surveyed in 2001 and 1,613,942 in 2007.	Bowel incontinence defined as more often than once a week.	Prevalence of FI was reported as 43.3% in 2001 and 43.1% in 2007.	No correlations reported.	HIGH

Ihnat et al. 2016; Czech Republic; Cross-sectional	N=588/740 residents from 4 NHs (mean age = 82 with SD=9.9); with 84.4% response rate); 74.5% women	FI classified according to the Cleveland Clinic Incontinence Score. Data sources: medical records and interviews with RNs	FI was noted in 336 (57.1%) of the residents. The majority of FI residents (57.8%) reported FI episodes 'several times a week' FI was frequently noted in residents aged 85 years and above.	Significant predictors: length of stay up to 6 years, comorbidities, UI, and cognitive impairment. Non-statistically significant correlates: advanced age and gender.	HIGH
Jerez-Roig et al. 2015; Brazil; Cross-sectional	N=321 residents, aged > 60 years (mean age = 81.5, with SD=9), from 10 NHs; 100% response rate. 75.4% women	FI defined as "the involuntary loss of liquid or solid stool". Data source: H4 of MDS version 3	FI was 42.68% (CI 95%, 37.39-48.15). DI was observed in 42.1% individuals, and only 0.2% isolated FI.	Statistically significant predictors from the multivariable analysis were impairment in cognitive capacity (PR=3.16; 95% CI: 1.19-5.20) and decline in functional capacity (PR=5.82; 95% CI: 3.78-8.95). Non-statistically significant correlates were age ≥81 (PR=1.13; 95% CI: 0.74-1.71), race (PR=1.37; 95% CI: 0.95-1.97), lack of care giver as the reason for admission (PR=1.27; 95% CI: 0.84-1.92), and stroke (PR=1.12; 95% CI: 0.65-1.93).	HIGH
Johanson et al. 1997; USA; Cross-sectional	N=388 residents, mean age = 83; *age range 31-103*; 76% women	FI was defined as any involuntary leakage of stool or soiling of undergarments.	**46%** of the residents were incontinent of faeces.	Diarrhoea, restricted mobility, and male gender were independently associated with FI. Incontinence was 1.5 times more in men and those younger than 65 years old.	MEDIUM
Kinnunen, O. 1991; Finland; Cross-sectional	N= 183 people living in Old People's Homes, mean age = 79.2 (SD=8.1). 72% women.	The authors did not define FI, or explain how FI was measured.	Of the 183 residents, 15% had FI.	No correlations reported.	LOW

Mandl et al. 2015; Austria; Cross-sectional	N=1397 NH residents in 16 NHs mean age = 83.7 years; SD=9.6; 80.1% response rate. 78.8% women	FI defined as “involuntary loss of faecal material, without any involuntary loss of urine”. DI defined as the loss of both urine and faecal material. Data source: Australian version of International Prevalence Measure of Care Problems was used to measure outcomes.	FI was 1% and DI was 69.2% (95% CI: 38.6-42.6). Residents aged ≥ 81 years reported more DI (58.6%), but less FI (2.9%) compared to those aged ≤ 80 years.	No correlations reported.	MEDIUM
Nelson and Furner 2005; USA; Longitudinal cohort study	181 Skilled Nursing Facilities provided resident based MDS data in 1992 (18,170 NH residents, with attrition of 7842 from 1992 to 1993). In 1992, 3850 residents were categorised as continent of both urine and faeces. The mean age of the continent residents was 84.4 years; 72% women.	**FI not defined**. The authors used the MDS to collect data.	Among the continent residents in 1992, 14.7% (n=567) were reported to have FI and 12.4% (n=479) were reported to have DI in 1993.	A multiple regression analysis showed positive associations with development of new FI: dementia, advanced age, and non-white. The strongest correlates were impairment in ADL (OR=3.1; 95% CI: 2.6-3.8) and the use of patient restraints. Arthritis, Body Mass Index, and male gender were found to be not statistically significant.	HIGH
Nelson et al. 1998; USA; Two cross-sectional studies	N=8471 (1992), mean age = 85.6 years, and N=7860 (1993), mean age = 84.9 years; 71% women.	FI not defined. Data were obtained from Wisconsin Centre for Health Statistics, using the MDS.	In 1992, 47% of the residents were reported to have FI (n=8,471); in 1993, 46% were reported to have FI (7, 860 residents).	Significant factors from a univariable analysis were: UI, tube feeding, any loss of ADL, diarrhoea, pressure ulcers, dementia, impaired vision, faecal impaction, constipation, stroke, male gender, rising age, and increasing body mass. Age, heart failure, arthritis, depression, diabetes, feeding oneself, inability to transfer from bed to chair, and loss of locomotion were inversely related to FI. Higher BMI was a protective factor.	HIGH

Peet et al. 1995; UK; Survey	N=3894 residents, aged ≥ 65 years (mean = 82.7, SD 7.8) from three out of eight settings surveyed.	Residents experiencing at least one incontinent episode weekly were defined as being incontinent of faeces.	All FI from three settings (local authority, private residential, and private nursing) was 10.5%.	No correlations reported.	LOW
Rodriguez et al. 2007; UK; Cross-sectional survey	186 CHs were eligible, of which 20 CHs were used for piloting; final surveys were returned by 66/186 CHs (35% response rate) from March to May 2005. The homes described a total of 1,869 residents aged ≥ 65 years.	FI not defined. A piloted survey – questionnaire was used as data collection tool.	Respondents indicated that 66 (4%) of the residents experienced FI, and 569 (31%) experienced DI. The prevalence of FI was higher in NH population compared to residential home population (80% vs 49%).	No correlations reported.	LOW
Saga et al. 2013; 2015; Norway; Population-based cross-sectional ***Note: One study reported in two papers: 2013 and 2015.***	N=930 residents, with the mean age = 85.5; SD=7.3 and a range=65-107 years; 75.9% women	FI in this study was defined as "involuntary leakage of stool at least a few times a month". A piloted questionnaire was used.	2.6% of residents had FI alone, and 40.2% had DI (2.6% + 40.2% = 42.8% all FI). Mean residency of residents in short-term care was 51.1 (SD=56.6) days; whereas, for long term care it was 881.9 (SD=871.0) days.	Statistically significant correlates from multivariable analysis were: diarrhoea (OR=7.33; 95% CI: 4.39-12.24), UI (OR=2.77; 95% CI: 1.73-4.42), dementia (OR=2.17; 95% CI: 1.28-3.68), Length of stay between 4-5 years (OR=2.65; 95% CI: 1.20-5.85), feeding dependent (OR=2.17; 95% CI; 1.26-3.71), dressing dependent (OR=4.03; 95% CI: 1.39-11.65), inability to use toilet (OR=7.37; 95% CI: 2.65-20.44), and immobility (OR=2.54; 95% CI: 1.07-6.00). Non-statistically significant correlates: age, gender, stroke, grooming, walk with support to toilet, unable to climb stairs, and bathing dependent. A protective factor was needing help to transfer between bed and chair (OR=0.49; 95% CI: 0.26-0.91; p=0.03).	HIGH
Thomas et al. 1987; UK; Case-control study	N=370 residents (70 men and 300 women), from 8 CHs; Median age=83.	FI was defined as involuntary passage or leakage of faeces twice or more a month.	Prevalence of FI was 16% at baseline. At 6 months follow-up, 76.9% of cases had continuing FI. 72.7% of men and 92% of women with FI also had DI.14% of the cases had died at follow-up compared to 7% of control.	No correlations reported.	LOW

Tobin and Brocklehurst 1986; UK; Quasi-RCT: Only cross-sectional baseline data are reported here.	30 Residential Homes, with 82 residents enrolled in the study.	FI was not defined.	FI occurring at least once weekly was found in 10.3% of residents. Characteristics of residents with FI: advanced age, poor mobility, neurological disease, and cognitive impairment	No correlations reported.	**LOW**
Wang et al. 2009; USA; Longitudinal cohort	N=4942 extended-stay NH residents admitted into 377 NHs in 2004; aged ≥ 65 years (mean = 84.3, SD =7.6). Length of follow-up was between 4 and 8 months;	FI was not defined. Data source: MDS record, nursing home characteristics from 2004 Minnesota state administrative data system and staffing levels from 2004 Minnesota Department of Human Services Annual Facility Survey.	FI at admission was 33.4% among the residents (no figure provided for FI at follow-up). This study reported that bowel incontinence was a nonsignificant predictor of subsequent ADL dependence.	No correlations reported.	**HIGH**

Abbreviations: NH(s) =nursing home(s); CH(s) =care home(s); LTCF=long-term care facilities; ADL=activities of daily living; MDS=minimum Data Set; SD=standard deviation; OSCAR =Online Survey, Certification, and Reporting; HR =hazard ratio; OR =odd ratio; RR =risk ratio; BMI =Body Mass Index.

Appendix 2: PhD Paper 1 Supplementary Table S2

Results of Search in Medline

Search Terms	Results
1. (prevalence or epidemiology or incidence).mp	1,382,426
2. (faecal incontinence or fecal incontinence or anal incontinence or bowel incontinence).mp	53,290
3. (older people or elderly people or frail people or resident$ or veteran$).mp	227,652
4. (care home$ or nursing home$ or residential home$ or veteran home$ or aged care facilit$ or skilled nursing facilit$ or long-term care facilit$).mp	49,323
5. 1 and 2	6764
6. 3 and 5	521
7. 4 and 6	271

Appendix 3: PhD Paper 1 Supplementary Table S3

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Studies on incontinence, where prevalence and/or incidence data on FI or double incontinence were available.	Studies solely on prevalence of urinary incontinence, where FI and/or double incontinence data cannot be obtained.
Studies relating to older people in care homes (e.g., nursing, or residential care homes), or where care home setting data could be extracted	Population-based studies, where focus is not care home residents.
Participants aged 60 years, or participants' mean age 65 years.	Participants' age <60 y, and/or mean age of participants <65 years.
Peer reviewed, scientific journals.	Abstracts only with no full-text publication.
Studies published in English language.	

Where a study was reported more than once from the same data, a decision was taken to include only one of the reports to avoid duplication and overstatement of results.

Appendix 4: PhD Paper 1 Supplementary Table S4

Risk of Bias and Quality Reporting for Included Studies: JBI Checklist for Prevalence Studies, With Slight Modification (Incorporating 2 Questions from JBI Critical Appraisal Checklist for Analytical Cross-Sectional Studies: CAC3 and CAC6)

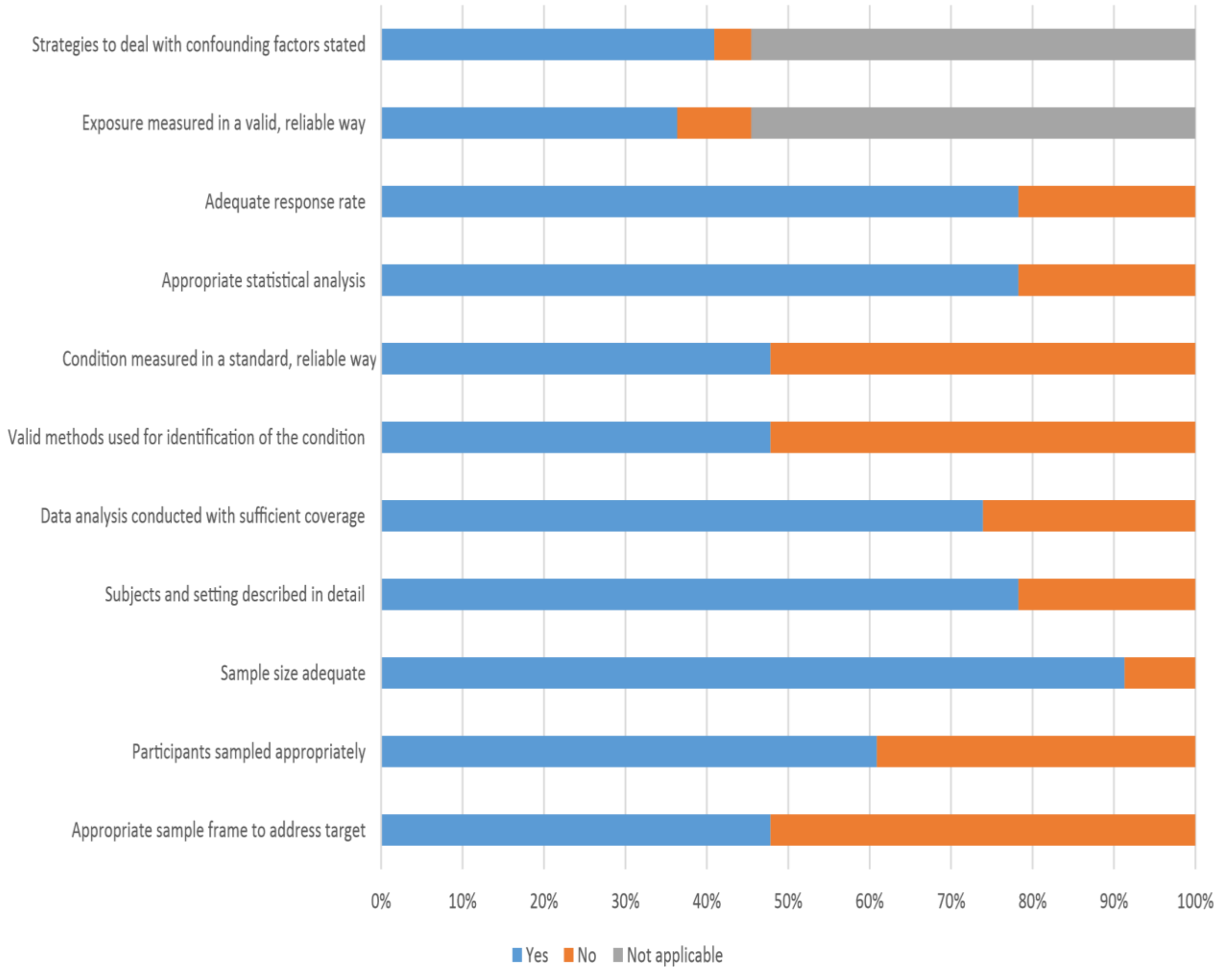
	1	2	3	4	5	6	7	8	9	CAC3	CAC6	Comments	Level
Aslan et al, 2009	Y	N	Y	Y	N	U	U	Y	N	Y	Y	Poor methodology and coverage bias/ poor response rate	Medium
Blekken et al, 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		High
Bliss et al, 2013	Y	U	Y	Y	N	Y	Y	Y	Y	N/A	N/A	Use of for-profit NH as possible bias	High
Bliss et al, 2017	N	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	Poorly described setting and how participants were sampled	High
Burgio et al, 1988	N	N	N	N	N	N	N	N	N	N/A	N/A	Poorly reported	Low
Capewell et al, 1986	Y	Y	Y	N	Y	U	U	Y	Y	N/A	N/A	Different research aim	Medium
Carryer et al, 2017	Y	Y	Y	Y	Y	Y	U	Y	Y	N/A	N/A		High
Chassagne et al, 1999	N	Y	Y	Y	Y	U	U	N	Y	U	Y	Unclear description of measurement and setting	Medium
Chiang et al, 2000	Y	U	Y	Y	Y	U	Y	Y	Y	Y	Y	Different aim	High
Harrington et al, 2008	Y	Y	Y	Y	Y	Y	Y	U	Y	N/A	N/A		High
Ihnat et al, 2016	U	Y	Y	Y	Y	Y	Y	Y	Y	Y	N		High
Jerez-Roig et al, 2015	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		High
Johanson et al, 1997	Y	U	Y	Y	Y	N	N	Y	Y	N	Y	Selection of care homes not clear; outcome measures not validated	Medium
Kinnunen, O. 1991	N	Y	Y	N	Y	U	U	Y	Y	N/A	N/A	Different study aim	Low
Mandl et al, 2015	N	Y	Y	Y	Y	N	N	Y	Y	N/A	N/A	Different aim; only 3.4% of NHs responded	Medium
Nelson and Furner 2005	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		High
Nelson et al, 1998	Y	U	Y	Y	N	Y	Y	Y	Y	Y	N	Population unknown	High
Peet et al, 1995	N	Y	Y	N	Y	N	U	Y	Y	N/A	N/A	Poor description of setting and participants	Low
Rodriguez et al, 2007	Y	Y	U	Y	U	U	U	U	N	N/A	N/A	Poor description of methods	Low
Saga et al, 2013	Y	Y	Y	Y	Y	N	Y	Y	Y	U	Y		High
Thomas et al, 1987	N	N	Y	U	U	N	N	Y	U	N/A	N/A		Low
Tobin and Brocklehurst 1986	N	Y	Y	N	Y	U	U	N	U	N/A	N/A	RCT; unclear outcome measure; poor description of setting and sample	Low

Wang et al, 2009	N	Y	Y	Y	Y	Y	Y	Y	Y	N/A	N/A	High

N, no; N/A, not applicable; NH, nursing home; U, unclear; Y, yes.

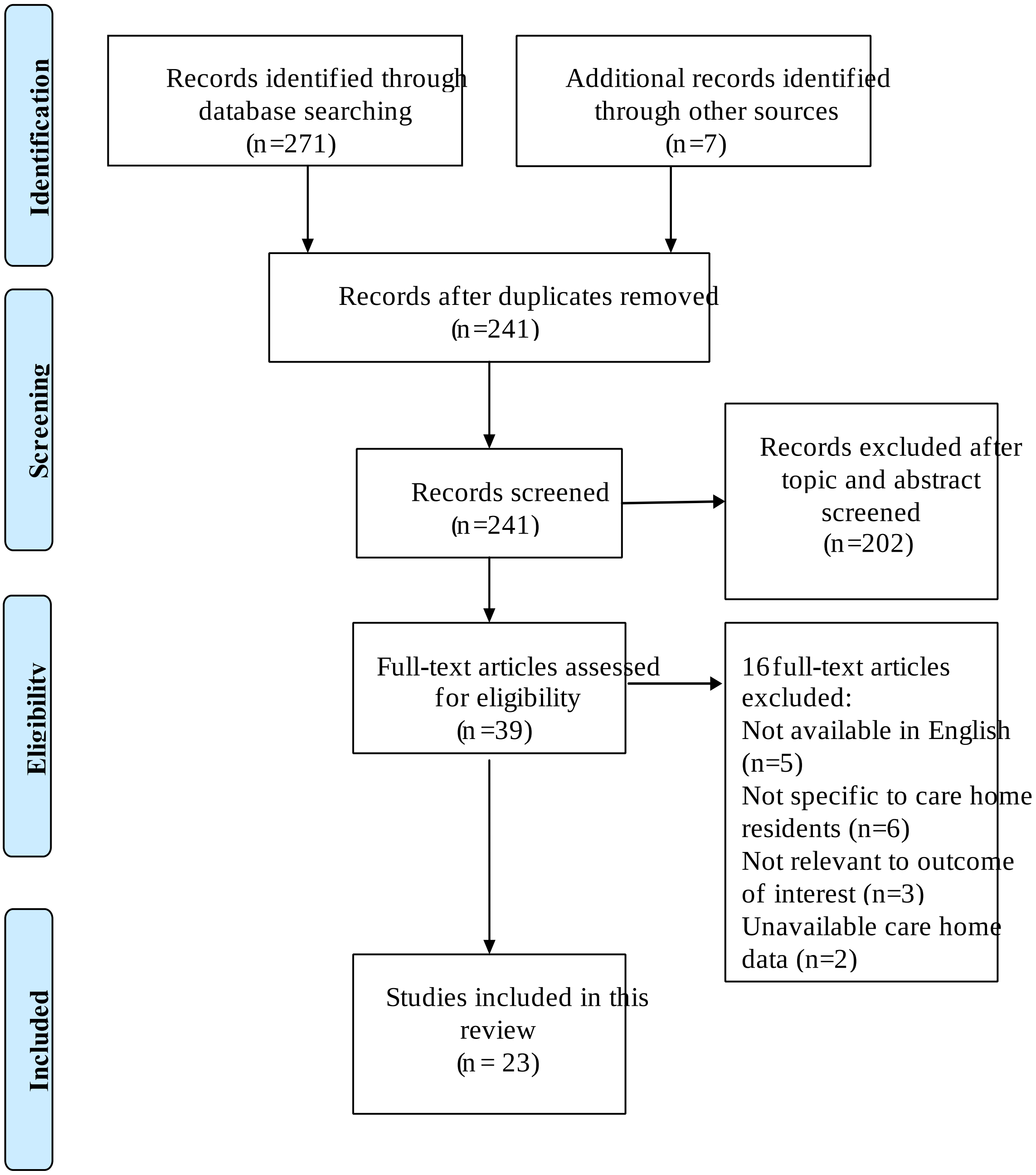
Appendix 5: PhD Paper 1: Supplementary Figure S1

Quality assessment of included studies



Supplementary Figure S1. Quality assessment of included studies (n = 23).

Appendix 6: PhD Paper 1 Supplementary Figure 2



Supplementary Figure S2. PRISMA flowchart of literature review process

Appendix 7: PhD Paper 2 Appendix 1

Cochrane Incontinence Specialised Register search terms Cochrane Incontinence Specialised Register

The terms that we used to search the Cochrane Incontinence Specialised Register on 17th October 2018 and updated on 03rd March 2022 are given below:
(design.cct* OR design.rct*)
AND
topic.faecal*

All searches were of the keyword field of EndNote 2021.

Cochrane Dementia and Cognitive Improvement Specialised Register (known as ALOIS)

ALOIS is maintained by the Information Specialists of the Cochrane Dementia and Cognitive Improvement Group and contains studies in the areas of dementia (prevention and treatment), mild cognitive impairment and cognitive improvement. The studies are identified from:

1. Monthly searches of a number of trial registers: ISRCTN; UMIN (Japan's Trial Register); the WHO portal (which covers ClinicalTrials.gov;ISRCTN; the Chinese Clinical Trials Register; the German Clinical Trials Register; the Iranian Registry of Clinical Trials and the Netherlands National Trials Register, plus others)
2. Quarterly search of the Cochrane Library’s Central Register of Controlled Trials (CENTRAL)
3. Six-monthly searches of a number of grey literature sources from ISI Web of Science Core Collection

The terms used by Anna Noel-Storr, Cochrane Information Specialist for the Cochrane Dementia and Cognitive Improvement Group, to search ALOIS on 29 November 2018, and 03rd March 2022 are given below: incontinence or incontinent or fecal or faecal or toileting.

For further details of ALOIS please see: https://dementia.cochrane.org/our-trials-register.

Appendix 8: PhD Paper 2 Appendix 2

Search methods for the integrated full systematic review of economic evidence

We performed additional searches for the integrated full systematic review of economic evidence, details of which are given below.

Economic evaluations

We searched the following databases:

- NHS EED on the Centre for Reviews and Dissemination website (covering to 31 December 2014); • MEDLINE on OvidSP (covering 1 January 1946 to the most recent available version); and
- Embase (on OvidSP) (covering 1 January 1980 to the most recent available version).

NHS EED is still available although the last searches performed for this database covered only up to the end of December 2014. In order to find relevant health economics papers published since December 2014 we will use the NHS EED search filters developed by the Centre for Reviews and Dissemination (to populate NHS EED) to search MEDLINE and Embase for economics studies covering from January 2015 onwards. The NHS EED search filters are freely available from: http://www.crd.york.ac.uk/crdweb/searchstrategies.asp.

We searched the NHS EED using the set of Cochrane Incontinence Specialised Register search terms covering faecal incontinence (detailed on the Group's webpages). MEDLINE and Embase were searched using the NHS EED filters as well as the set of Cochrane Incontinence Specialised Register search terms covering faecal incontinence (detailed on the Group's webpages).

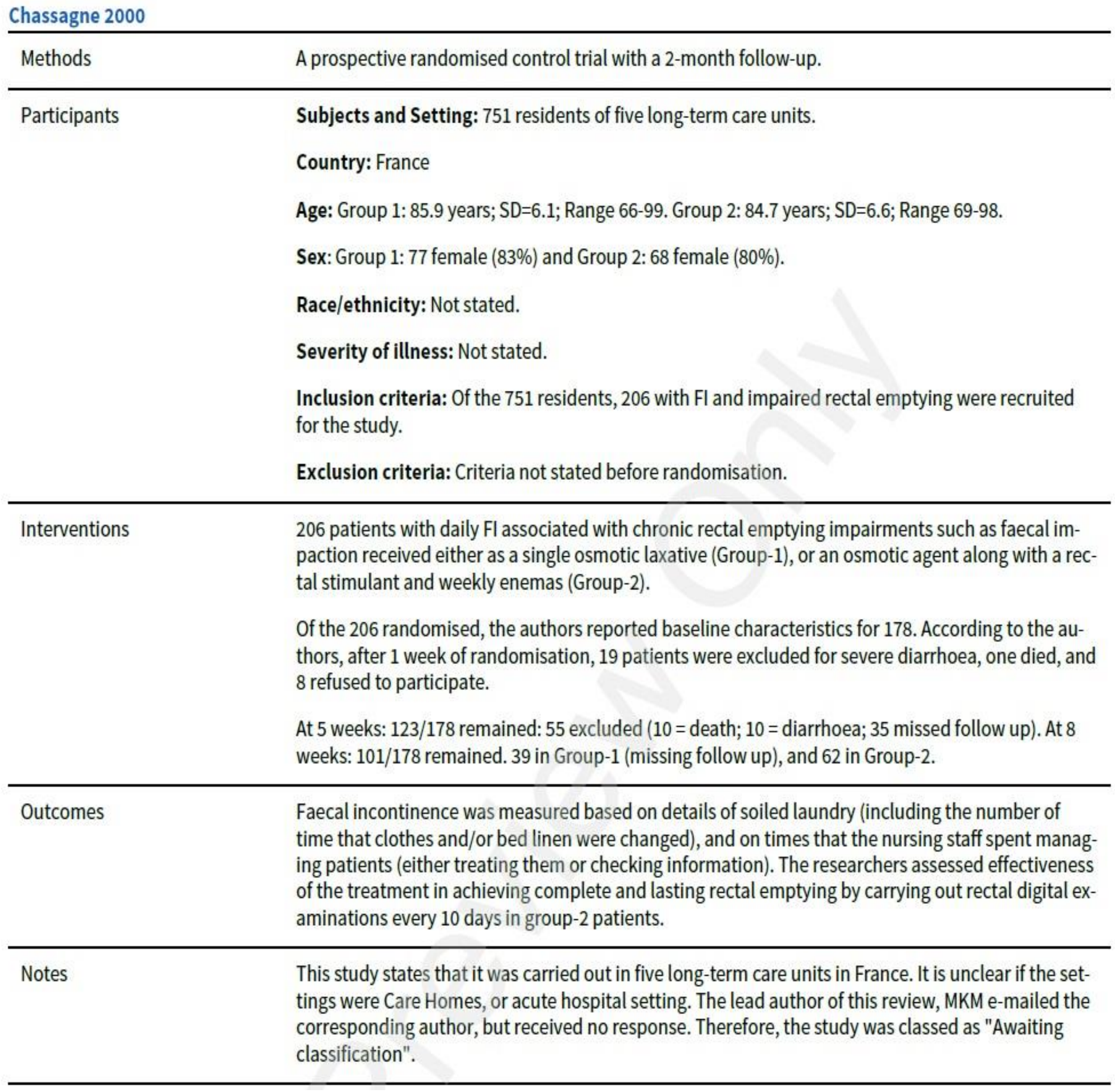
We explored the usefulness of an additional search of the HTA database, also on the CRD website, depending on a fuller report of the work of Arber 2018.

We did not impose any limitations on the searches other than by year of addition of references to MEDLINE and Embase from 1 January 2015 onwards.

Cost analyses and comparative resource utilisation studies

We used search strategies to locate cost analyses and comparative resource utilisation studies, but the included studies did not carry out such economic analyses.

Appendix 9: PhD Paper 2 Characteristics of studies awaiting classification



Chassagne 2000

Methods	A prospective randomised control trial with a 2-month follow-up.
Participants	**Subjects and Setting:** 751 residents of five long-term care units. **Country:** France **Age:** Group 1: 85.9 years; SD=6.1; Range 66-99. Group 2: 84.7 years; SD=6.6; Range 69-98. **Sex**: Group 1: 77 female (83%) and Group 2: 68 female (80%). **Race/ethnicity:** Not stated. **Severity of illness:** Not stated. **Inclusion criteria:** Of the 751 residents, 206 with FI and impaired rectal emptying were recruited for the study. **Exclusion criteria:** Criteria not stated before randomisation.
Interventions	206 patients with daily FI associated with chronic rectal emptying impairments such as faecal impaction received either as a single osmotic laxative (Group-1), or an osmotic agent along with a rectal stimulant and weekly enemas (Group-2). Of the 206 randomised, the authors reported baseline characteristics for 178. According to the authors, after 1 week of randomisation, 19 patients were excluded for severe diarrhoea, one died, and 8 refused to participate. At 5 weeks: 123/178 remained: 55 excluded (10 = death; 10 = diarrhoea; 35 missed follow up). At 8 weeks: 101/178 remained. 39 in Group-1 (missing follow up), and 62 in Group-2.
Outcomes	Faecal incontinence was measured based on details of soiled laundry (including the number of time that clothes and/or bed linen were changed), and on times that the nursing staff spent managing patients (either treating them or checking information). The researchers assessed effectiveness of the treatment in achieving complete and lasting rectal emptying by carrying out rectal digital examinations every 10 days in group-2 patients.
Notes	This study states that it was carried out in five long-term care units in France. It is unclear if the settings were Care Homes, or acute hospital setting. The lead author of this review, MKM e-mailed the corresponding author, but received no response. Therefore, the study was classed as "Awaiting classification".

Appendix 10: PhD Paper 2 Characteristics of included studies and their risk of bias

Blekken 2015	*Study characteristics*
Methods	**Study design:** RCT: Three arm cluster parallel group RCT carried out over three months (Exact date not reported by the authors)
Participants	**Subjects and Setting:** 73 residents and 22 registered nurses from 3 nursing homes. **Country:** Norway **Age:** Mean 86 (SD 10.14) **Sex:** 48 (77.4%) females **Race/ethnicity:** Not stated. **Severity of illness:** Not stated. **Inclusion criteria:** None stated – all registered nurses and residents on units included **Exclusion criteria:** None stated – all registered nurses and residents on units included
Interventions	**Intervention group 1**: Control: The control group did not receive any educational program and continued with ordinary practice. **Intervention group 2:** SI (single intervention): FI guideline; 7-hour educational meeting for registered nurses: interactive workshop targeting knowledge, attitudes and skills. Case based discussion on the guideline. **Intervention group 3**: MI (mixed intervention): FI guideline; 7-hour educational meeting for registered nurses: interactive workshop targeting knowledge, attitudes, and skills. Case based discussion on the guideline. Recruitment of local opinion leader who had additional 1.5 educational meeting on how to fulfil their role. Educational outreach visits for all care staff: 6 sessions of 1.5 hours each. In this study, SI comprised of one 7-hour educational meeting, defined by the Cochrane Effective Practice and Organization of Care (EPOC) as “participation of healthcare providers in conference, lectures, workshops, or training”. The researchers organised the educational meeting as an interactive workshop that targeted knowledge, attitudes, and skills of nurses. The MI, on the other hand, comprised of two more elements: recruitment of a local opinion leader (use of providers nominated by their colleges as educationally influential) and educational outreach visits (use of a trained person who meets with providers in their practice setting to give information with the intent of changing the providers’ practice.
Outcomes	1. InterRAI long term care facilities assessment system H3: Bowel continence 2. St Marks anal incontinence score 3. Nurses knowledge score
Funding sources	The Norwegian Nurses Organization funded the study

Blekken 2015: Risk of Bias		
Bias	Authors' judgement	Support for judgement
Random sequence generation	Unclear risk	Not stated
Allocation concealment (selection bias)	Unclear risk	Not stated
Blinding of participants and personnel (performance bias) All outcomes	High risk	N/A as not possible
Blinding of outcome assessment (detection bias)	High risk	Not possible
Incomplete outcome data (attrition bias) All outcomes	Low risk	Some attrition (e.g., death and withdrawal) mentioned– not clear if biased: pilot study only
Selective reporting (reporting bias)	Unclear risk	Not all measures listed are reported
Other bias	Unclear	

Booth 2013	*Study characteristics*
Methods	**Study design:** Randomised controlled trial (Pilot randomised single-blind, placebo-controlled trial)
Participants	**Subjects and Setting:** 30 residents from 7 residential homes and 3 sheltered accommodations. **Country:** United Kingdom **Age:** The mean age of participants was 84.2 years (SD=10.0). **Sex:** Most were women (80%, n = 24). **Race/ethnicity:** Not stated. **Severity of illness:** Not stated. **Inclusion criteria:** (1) men and women older than 65 in residential care home settlings or sheltered accommodation with bothersome lower urinary tract symptoms (LUTS), UI, FI, or constipation; (2) capacity to provide ongoing informed consent to participate. **Exclusion criteria:** (1) pacemaker in situ, (2) leg ulcers or broken skin on lower limb, (3) peripheral vascular disease, (4) reduced/absent sensation at the electrode sites, (5) moderate or severe cognitive impairment or learning difficulties, (6) urinary tract infection (UTI) on assessment, or (7) clinical diagnosis of only stress UI.
Interventions	Twelve 30-minutes sessions of Transcutaneous posterior tibial nerve stimulation (TPTNS) vs Sham stimulation (placebo). In the TPTNS group, residents received twelve sessions, each with 30 minutes duration, delivered twice weekly over a continuous 6-week period. Two self-adhesive surface electrodes were positioned with the negative electrode 2 cm behind the redial malleolus and the positive electrode 10 cm proximal to it. The sham stimulation group underwent the same procedure; however, the surface electrodes were positioned to avoid the posterior tibial nerve with the negative electrode on the lateral malleolus and the positive electrode proximal to it.
Outcomes	The ICIQ-SF, ICIQ Bowel questions, and AUASI were used to measure bladder and bowel symptoms (only bowel symptoms were extracted for this review).
Funding sources	The study was funded by Glasgow Caledonian University Institute for Applied Health Research Pump Priming Award.

Booth 2013: Risk of Bias		
Bias	Authors' judgement	Support for judgement
Random sequence generation	Low risk	Computer generated online
Allocation concealment (selection bias)	Low risk	Computer generated online
Blinding of participants and personnel (performance bias) All outcomes	Low risk	Outcome group: All staff and participants blinded. The investigators doing the interventions were not blinded – but it is probably impossible to "blind" the persons doing this kind of interventions, so it is probably correct to state Low risk of bias anyway
Blinding of outcome assessment (detection bias)	Unclear risk	Outcome group: Unclear
Incomplete outcome data (attrition bias) All outcomes	Low risk	Attrition: withdrawal from intervention and infection
Selective reporting (reporting bias)	Unclear risk	Not possible to separate FI from others

Schnelle 2002	*Study characteristics*
Methods	Study design: Randomized controlled trial with blinded assessments of outcomes at three points over 8 months
Participants	**Setting:** 190 of 256 incontinent residents (from whom baseline assessments were successfully completed) from 4 nursing homes. **Country:** United States of America **Age (mean; SD)**: Control Group: 88; 7 and Intervention Group: 87; 8 **Sex:** 81% female **Race/ethnicity:** Not stated. **Severity of illness:** Not stated. **Inclusion Criteria:** Not stated. **Exclusion Criteria:** Residents on post–acute skilled care units or terminally ill
Interventions	190 residents were randomised into intervention (n=94) and control (n=96) groups using a computerised randomisation program completed after baseline assessments. The intervention group received the intervention for 32 weeks. One hundred forty-eight of the residents completed the 32-weeks intervention: Intervention Group (n=74), and Control Group (n=74). The intervention was implemented every 2 hours, 5 days a week, from about 8:00 a.m. to 4:30 p.m., for a possible total of four care episodes per day. During each episode of care provided by research staff, residents were prompted to toilet and were changed if they were wet. No effort was made to influence the incontinence care practices of NH staff during hours when the resident was not being provided care by research staB. Before or after this incontinence care, staB encouraged residents to walk or, if non-ambulatory, to wheel their chairs and to repeat sit-to-stands up to eight times using the minimum level of human assistance possible. During one episode per day, each resident, usually while in bed, was given upper body resistance training (arm curls or arm raises). Residents were positioned at 45 degrees in bed and asked to complete an arm raise or arm curl with each arm. The arm raise and arm curl exercises were conducted on separate days. A one-repetition maximum lift was used to evaluate strength and took place at baseline and at 8 and 32 weeks after baseline. Before and after each care episode, residents were offered fluids. 172 (91%) of the residents (85 intervention and 87 control) completed the 8-week (post-1) assessments, and 148 (78%) of the residents (74 intervention and 74 control) completed the 32-week (post-2) assessments.
Outcomes	Medical comorbidity was determined at baseline in two ways. First, research staff obtained a simple count of diagnoses from the resident’s medical record. Second, a study physician used baseline information from the medical record and a brief physical examination of the resident to rate comorbidity using the Cumulative Illness Rating Scale for Geriatrics (CIRS-G). To assess residents' preference for key components of the intervention, the researchers used questionnaires that included four questions: “How many times during the day would you like someone to help you to use the toilet? Change your adult pad? Walk? Wheel your chair?”
Funding sources	The National Institutes of Health: Mobility and Incontinence Management Effects on Sickness and Grant and the National Institute on Aging funded this study.

Schnelle 2002: Risk of Bias		
Bias	Authors' judgement	Support for judgement
Random sequence generation	Unclear risk	Not mentioned
Allocation concealment (selection bias)	Unclear risk	Not mentioned
Blinding of participants and personnel (performance bias) All outcomes	High risk	Independent outcome assessors could not blind researchers implementing the intervention
Blinding of outcome assessment (detection bias)	Unclear risk	Not mentioned
Incomplete outcome data (attrition bias) All outcomes	Low risk	78% reported at 32 weeks; most attrition death or prolong illness
Selective reporting (reporting bias)	Unclear risk	None apparent

Schnelle 2010	*Study characteristics*
Methods	**Study design:** Randomized controlled trial
Participants	**Subjects and Setting:** 112 residents from 6 nursing homes. **Country:** United States of America **Age (mean; SD):** Control Group: 86.1; 10.5; Intervention Group: 85.8; 9.4 **Sex:** 81% female **Race/ethnicity:** Not stated. **Severity of illness:** Not stated. **Inclusion Criteria:** All subjects with FI. **Exclusion Criteria:** Subjects who were comatose and/or short-term stay residents as defined by Medicare.
Interventions	Two groups: Intervention (n=65) and Control (n=60). Those that completed the 12-week intervention: Intervention (n=58) and Control (n=54). Intervention subjects were offered toileting assistance, exercise, and choice of food and fluid snacks every 2 hours for 8 hours per day over 3 months. During each intervention episode, the resident was checked for incontinence and prompted to use the toilet (intervention component 1). They were offered a choice of food and fluid snack items (intervention component 3) and prompted to exercise (repeat sit-to-stands and walking or wheelchair propulsion) for up to 5 minutes per care episode (intervention component 2).
Outcomes	Primary outcome measures included frequency measures of incontinent and continent urinary and faecal voids. Appropriate toileting percentage was calculated by dividing the number of voids in the toilet by the total number of voids. The total number of bowel movements (incontinent + continent) was calculated per participant per day.
Funding sources	This research was supported by Grants AG2355501A1 and AGO28748 provided by the National Institute of Aging and the Veterans Affairs Medical Research funds.

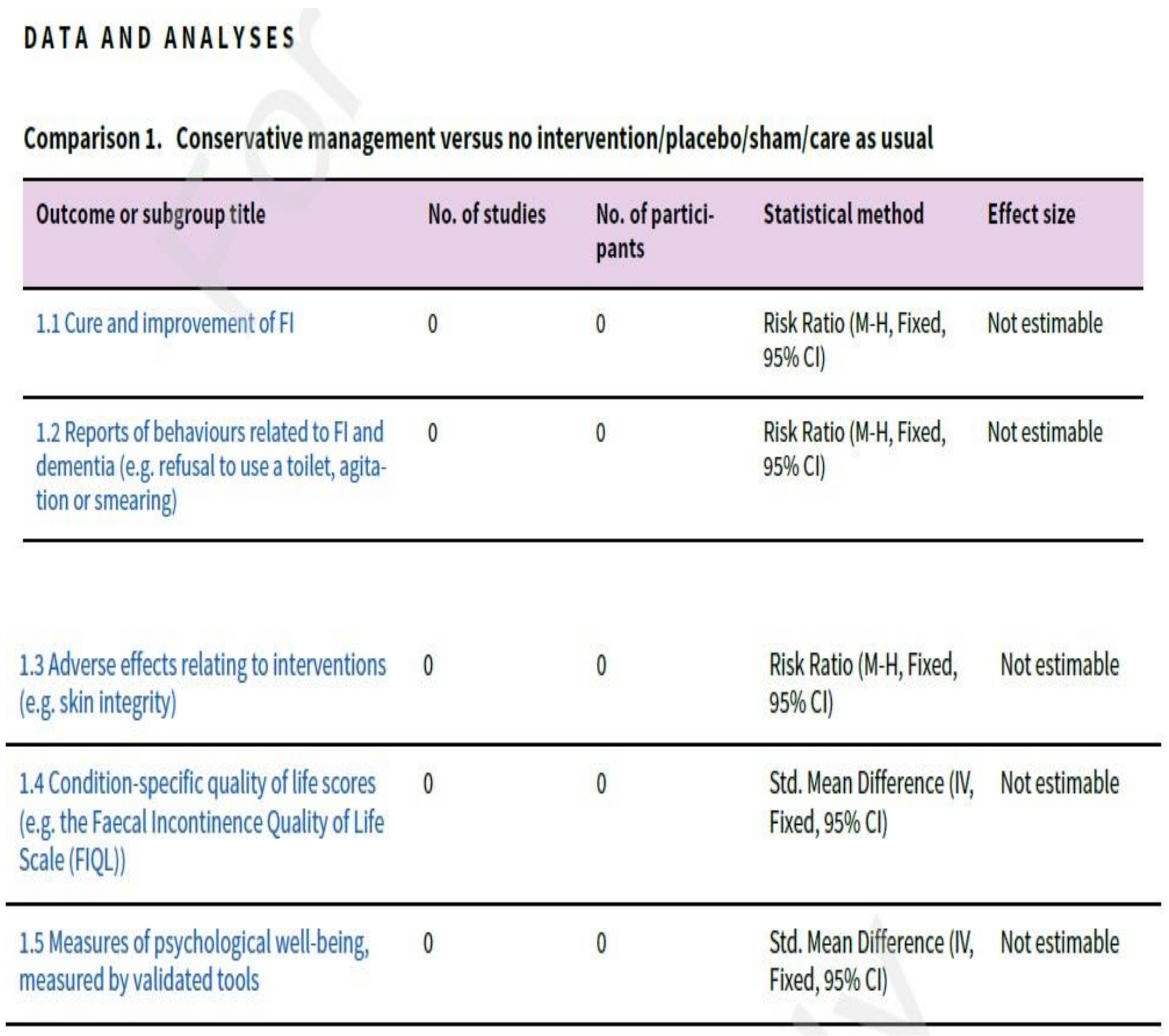
Schnelle 2010: Risk of Bias		
Bias	Authors' judgement	Support for judgement
Random sequence generation	Low risk	Randomized using a table of random numbers
Allocation concealment (selection bias)	Low risk	Allocation followed the random sequence generation
Blinding of participants and personnel (performance bias) All outcomes	High risk	Blinding of residents and research staff doing the intervention not possible
Blinding of outcome assessment (detection bias)	High risk	It was the research staff who implemented the intervention and checked for FI (and UI) and did the assessment. It is unclear whether it was the same research staff doing the intervention and doing the pre and post assessments
Incomplete outcome data (attrition bias) All outcomes	Low risk	Attrition: death and lost to follow-up, withdrawal and prolonged hospitalisation
Selective reporting (reporting bias)	Unclear risk	Not mentioned

Appendix 11: PhD Paper 2 Characteristics of excluded studies

Study	**Reason for exclusion**
Bates-Jensen 2003	This study investigated skin health outcomes when incontinence (urinary and faecal) and exercise interventions are provided. The study neither addresses nor reports outcomes of interest in this review (e.g., reduction of FI episodes).
Gotestam 1977	Geriatric psychiatry at hospital - not a care home population.
Hope 1986	Population: Not people with FI. This study was on constipation and the authors did not measure FI (Handbook, Section 4.6.3; Version 6).
Karam 1994	Not a randomised controlled trial.
Kinnunen 1987	Study carried out in hospital setting.
Mamtani 1989	Population: Not people with FI. The study compared two forms of laxatives without FI measures (Handbook, Section 4.6.3; Version 6).
Palese 2010	Population: Not people with FI (Handbook, Section 4.6.3; Version 6).
Passmore 1993	FI. Also nursing home data indistinguishable from hospital data Version 6).
Pitkala 2007	Population: Not people with FI. This study measured bowel movement frequency, not FI (Handbook, Section 4.6.3; Version 6).
Pittman 2011	Study carried out in Intensive Care Setting.
Rantz 2012	Population: Not people with FI (Handbook, Section 4.6.3; Version 6).
Schnelle 2003	Population: Urinary incontinence, not FI. The study focused on cost of assessing and treating acute conditions other than FI. This study had previously been reported in 2002 (Handbook, Sections 4.6.2; 5.2.1; Version 6).
Seinela 2009	Population: Not people with FI (Handbook, Section 4.6.3; Version 6).
Simmons 2004	Population: Urinary incontinence, not FI (Handbook, Section 4.6.3; Version 6).
Tobin 1986	Not randomised controlled trial.
Wilson 1975	Occurred in hospital setting.

Abbreviations: FI = faecal incontinence; UI = urinary incontinence

Appendix 12: PhD Paper 2 Data analysis

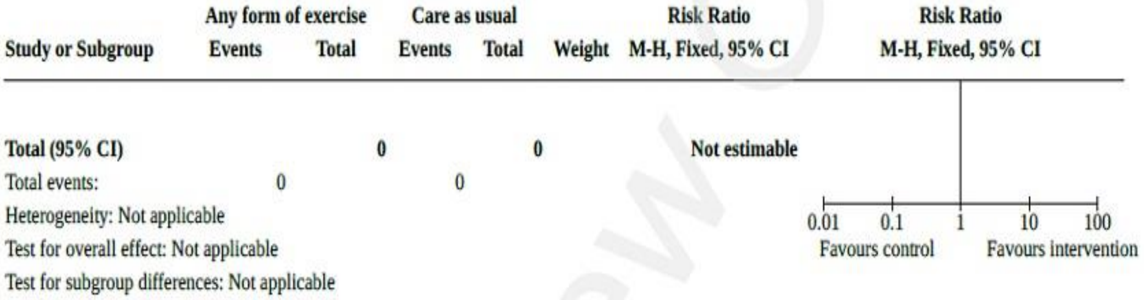


DATA AND ANALYSES

Comparison 1. Conservative management versus no intervention/placebo/sham/care as usual

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1.1 Cure and improvement of FI	0	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable
1.2 Reports of behaviours related to FI and dementia (e.g. refusal to use a toilet, agitation or smearing)	0	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable
1.3 Adverse effects relating to interventions (e.g. skin integrity)	0	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable
1.4 Condition-specific quality of life scores (e.g. the Faecal Incontinence Quality of Life Scale (FIQL))	0	0	Std. Mean Difference (IV, Fixed, 95% CI)	Not estimable
1.5 Measures of psychological well-being, measured by validated tools	0	0	Std. Mean Difference (IV, Fixed, 95% CI)	Not estimable

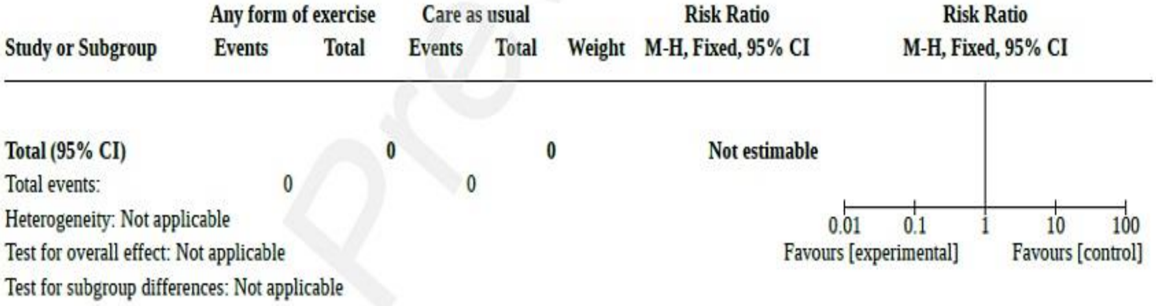
Analysis 1.1. Comparison 1: Conservative management versus no intervention/placebo/sham/care as usual, Outcome 1: Cure and improvement of FI



	Any form of exercise		Care as usual			Risk Ratio
Study or Subgroup	Events	Total	Events	Total	Weight	M-H, Fixed, 95% CI
Total (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

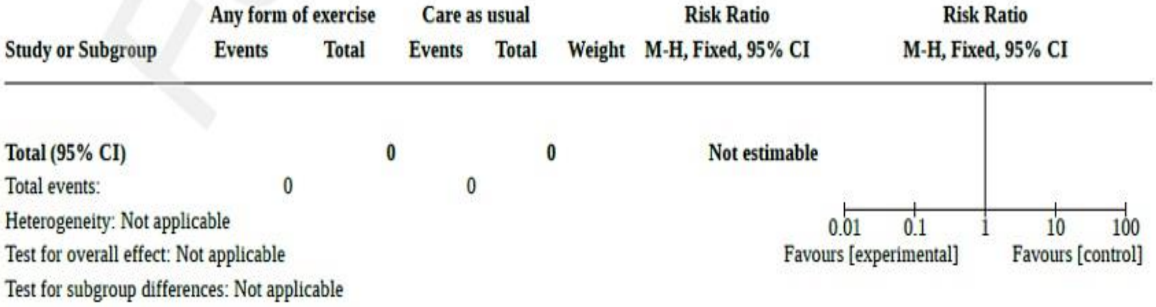
Analysis 1.2. Comparison 1: Conservative management versus no intervention/placebo/sham/care as usual, Outcome 2: Reports of behaviours related to FI and dementia (e.g. refusal to use a toilet, agitation or smearing)



	Any form of exercise		Care as usual			Risk Ratio
Study or Subgroup	Events	Total	Events	Total	Weight	M-H, Fixed, 95% CI
Total (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

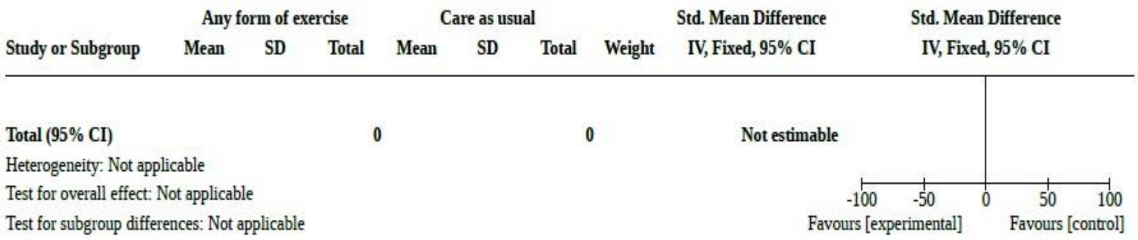
Analysis 1.3. Comparison 1: Conservative management versus no intervention/placebo/sham/care as usual, Outcome 3: Adverse effects relating to interventions (e.g. skin integrity)



	Any form of exercise		Care as usual			Risk Ratio
Study or Subgroup	Events	Total	Events	Total	Weight	M-H, Fixed, 95% CI
Total (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

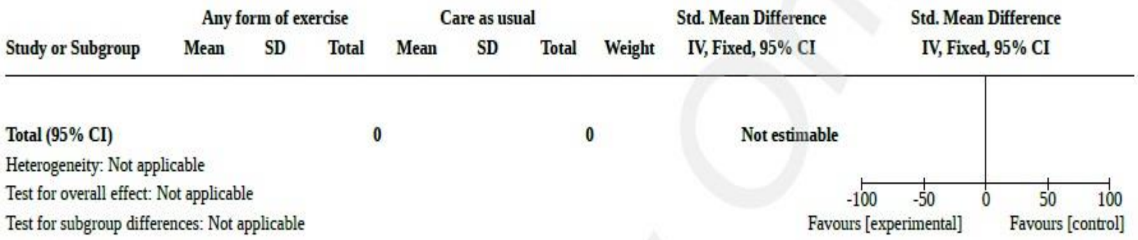
Analysis 1.4. Comparison 1: Conservative management versus no intervention/placebo/sham/care as usual, Outcome 4: Condition-specific quality of life scores (e.g. the Faecal Incontinence Quality of Life Scale (FIQL))



Study or Subgroup	Any form of exercise Mean	SD	Total	Care as usual Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI	Std. Mean Difference IV, Fixed, 95% CI
Total (95% CI)			0			0		Not estimable	

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

Analysis 1.5. Comparison 1: Conservative management versus no intervention/placebo/sham/care as usual, Outcome 5: Measures of psychological well-being, measured by validated tools



Study or Subgroup	Any form of exercise Mean	SD	Total	Care as usual Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI	Std. Mean Difference IV, Fixed, 95% CI
Total (95% CI)			0			0		Not estimable	

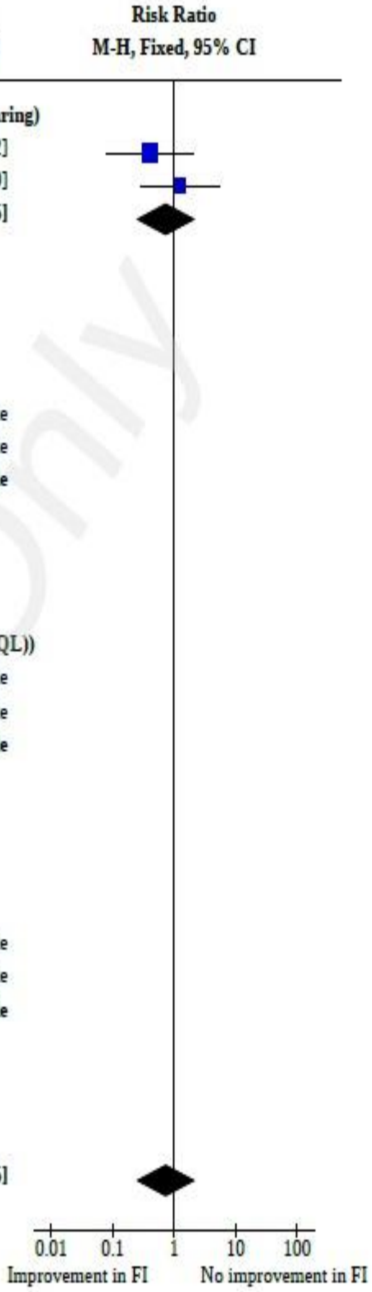
Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

Comparison 2. Any form of exercise (e.g., mobility, endurance, strength) vs Care as usual

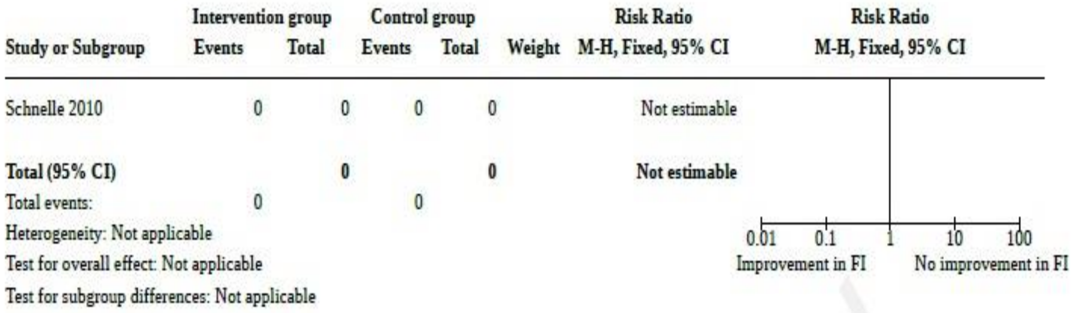
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
2.1 Improvement of FI	2	259	Risk Ratio (M-H, Fixed, 95% CI)	0.73 [0.26, 2.05]
2.1.1 Reports of behaviours related to FI and dementia (e.g. refusal to use a toilet, agitation or smearing)	2	259	Risk Ratio (M-H, Fixed, 95% CI)	0.73 [0.26, 2.05]
2.1.2 Adverse effects relating to interventions (e.g., skin integrity)	2	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable
2.1.3 Condition-specific quality of life scores (e.g., the Faecal Incontinence Quality of Life Scale (FIQL))	2	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable
2.1.4 Measures of psychological well-being, measured by validated tools	2	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable

Analysis 2.1. Comparison 2: Any form of exercise (e.g., mobility, endurance, strength) vs Care as usual, Outcome 1: Improvement of FI

Study or Subgroup	Intervention group Events	Intervention group Total	Control group Events	Control group Total	Weight	Risk Ratio M-H, Fixed, 95% CI
2.1.1 Reports of behaviours related to FI and dementia (e.g. refusal to use a toilet, agitation or smearing)						
Schnelle 2002	2	73	5	74	61.5%	0.41 [0.08 , 2.02]
Schnelle 2010	4	58	3	54	38.5%	1.24 [0.29 , 5.29]
Subtotal (95% CI)		**131**		**128**	**100.0%**	**0.73 [0.26 , 2.05]**
Total events:	6		8			
Heterogeneity: Chi² = 1.03, df = 1 (P = 0.31); I² = 3%						
Test for overall effect: Z = 0.60 (P = 0.55)						
2.1.2 Adverse effects relating to interventions (e.g., skin integrity)						
Schnelle 2002	0	0	0	0		Not estimable
Schnelle 2010	0	0	0	0		Not estimable
Subtotal (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			
Heterogeneity: Not applicable						
Test for overall effect: Not applicable						
2.1.3 Condition-specific quality of life scores (e.g., the Faecal Incontinence Quality of Life Scale (FIQL))						
Schnelle 2002	0	0	0	0		Not estimable
Schnelle 2010	0	0	0	0		Not estimable
Subtotal (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			
Heterogeneity: Not applicable						
Test for overall effect: Not applicable						
2.1.4 Measures of psychological well-being, measured by validated tools						
Schnelle 2002	0	0	0	0		Not estimable
Schnelle 2010	0	0	0	0		Not estimable
Subtotal (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			
Heterogeneity: Not applicable						
Test for overall effect: Not applicable						
Total (95% CI)		**131**		**128**	**100.0%**	**0.73 [0.26 , 2.05]**
Total events:	6		8			
Heterogeneity: Chi² = 1.03, df = 1 (P = 0.31); I² = 3%						
Test for overall effect: Z = 0.60 (P = 0.55)						
Test for subgroup differences: Not applicable						



Analysis 3.1. Comparison 3: Food and fluid intake vs Care as usual, Outcome 1: Improvement in FI



Study or Subgroup	Intervention group Events	Intervention group Total	Control group Events	Control group Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Schnelle 2010	0	0	0	0		Not estimable
Total (95% CI)		**0**		**0**		**Not estimable**
Total events:	0		0			

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

Comparison 4. Transcutaneous Posterior Tibial Nerve Stimulation (TPTNS) vs Care as usual

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
4.1 Improvement in FI	1	30	Risk Ratio (M-H, Fixed, 95% CI)	0.67 [0.39, 1.14]

Analysis 4.1. Comparison 4: Transcutaneous Posterior Tibial Nerve Stimulation (TPTNS) vs Care as usual, Outcome 1: Improvement in FI

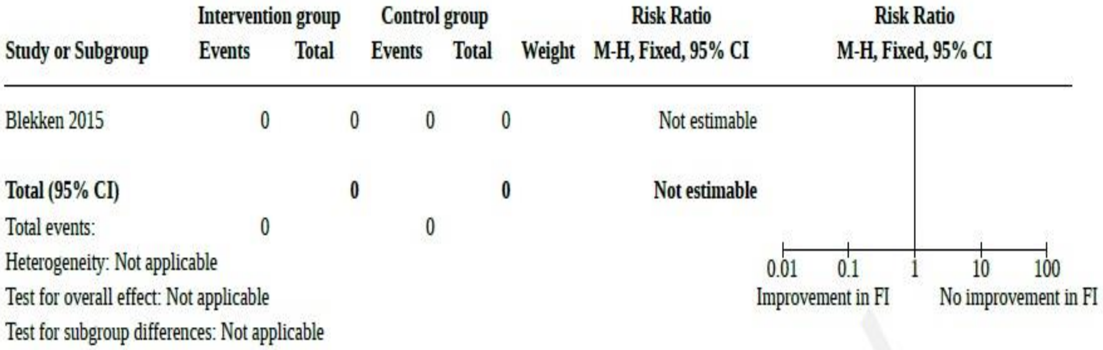
Study or Subgroup	Intervention group Events	Intervention group Total	Control group Events	Control group Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Booth 2013	8	15	12	15	100.0%	0.67 [0.39 , 1.14]
Total (95% CI)		**15**		**15**	**100.0%**	**0.67 [0.39 , 1.14]**
Total events:	8		12			

Heterogeneity: Not applicable
Test for overall effect: Z = 1.48 (P = 0.14)
Test for subgroup differences: Not applicable

Comparison 5. Single educational intervention vs Care as usual

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
5.1 Improvement in FI	1	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable

Analysis 5.1. Comparison 5: Single educational intervention vs Care as usual, Outcome 1: Improvement in FI



Study or Subgroup	Intervention group Events	Intervention group Total	Control group Events	Control group Total	Weight	Risk Ratio M-H, Fixed, 95% CI	Risk Ratio M-H, Fixed, 95% CI
Blekken 2015	0	0	0	0		Not estimable	
Total (95% CI)		**0**		**0**		**Not estimable**	
Total events:	0		0				

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

omparison 6. Multiple educational intervention vs Care as usual

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
6.1 Improvement in FI	1	0	Risk Ratio (M-H, Fixed, 95% CI)	Not estimable

Analysis 6.1. Comparison 6: Multiple educational intervention vs Care as usual, Outcome 1: Improvement in FI

Study or Subgroup	Intervention group Events	Intervention group Total	Control group Events	Control group Total	Weight	Risk Ratio M-H, Fixed, 95% CI	Risk Ratio M-H, Fixed, 95% CI
Blekken 2015	0	0	0	0		Not estimable	
Total (95% CI)		**0**		**0**		**Not estimable**	
Total events:	0		0				

Heterogeneity: Not applicable
Test for overall effect: Not applicable
Test for subgroup differences: Not applicable

Appendix 13: The CMO configuration that enabled development of FINCH programme theories

Theory area	Resource	Context	Mechanism	Outcome
Clinician-led support and review	• Clinician-led assessment and ongoing support and review. • Jointly agreed approaches to the promotion of continence and alternatives to the use of pads.	• Care home staff do not have the authority or expertise to be able to complete an assessment for FI, particularly digital rectal examination, diagnosis of diarrhoea, or drug review. • Shared communication and review of residents' needs. • Care home staff observe and document the changes in the resident, and this is fed back into the assessment and/or review process.	• Staff are confident to accept the delegated responsibility of assessment and management. • Increased staff awareness and involvement in continence care. • Practices that support effective continence care are continually reinforced.	✓ Reduction in FI. ✓ Effective continence care. ✓ Improved resident well-being.
Ongoing teaching, review and feedback to care home staff on the assessment and management of FI.	• Training and support for staff on FI.	• Staff have allocated time to complete training. • Staff get feedback on how they are delivering continence care. • Staff knowledge and understanding of how to prevent, recognise and treat causes of FI.	• Staff prioritise and engage with residents and staff to discuss, plan and document their FI-related work. • Staff confidence about delivering continence care.	✓ More appropriate measures used to reduce and manage FI. ✓ Staff value this work as skilled work.
	• Training programme (in Psychosocial interventions).	• Training programme delivered to all staff AND family members – fosters a common approach.	• Triggers a shared understanding about challenging behaviours and that they can make a difference.	✓ Staff groups and family work together to provide the care of the resident and reduce use of antipsychotic drugs.
	• Single educational input. • Workshop with knowledge test plus champion using case examples and ongoing resources. • Use of FI guideline with FI assessment/care planning	• Large and changing staff group with range of skills. • Large, changing workforce from different cultural backgrounds. • Learning reinforced by confident/competent staff group in electronic systems.	• Absence of group response to knowledge of best practice. • No time. • Opinion leader engaged with some staff but not all.	✓ Loss of focus on FI and unsustain changes to rate of FI in residents. ✓ Limited reduction in frequency of FI (note the small numbers). ✓ Limited use of electronic record with FI assessment

	on electronic patient record.	• RNs only to undertake assessments and direct care plans. • ‘Nobody’ read and followed the directions.	• Few opportunities to organise meetings between work demands. • Limited time. • Uncertainty how to communicate care in electronic patient record. • Division of labour theory apportions status – so many non-RN staff disengaged.	and care planning and then implementation.
Knowledge about the management of constipation for older people with dementia.	• Knowledge/training on constipation. • Regular review of constipation. • Regular toileting.	• Focus on the prevention, treatment and management of constipation and contributory factors.	• Prompts staff to review residents’ medication, fluid and nutrition intake, bowel function and activities that reduce the risk of constipation, such as exercise.	✓ Less constipation and less FI that is secondary to constipation. ✓ Improved bowel health (nutritional status and functional abilities).
	• Knowledge that constipation needs to be reduced.	• Clinician-led bowel and continence assessment as well as increased mobilisation, increased fluids and a prompted voiding intervention. • Routine use of laxatives in care home and lack of individualised assessment. • A challenging patient group, patient and family experience, physical and organisational working conditions and professional challenges.	• Interaction of mobilisation, fluids and prompted voiding schedule plus the additional staff resources (research staff) triggers more time spent on FI-related care. • Triggers overuse of laxatives and acceptance of FI as inevitable consequence. • Triggers compromise of care and prioritisation of emptying of bowels and use of ‘any method necessary’ to achieve goal: task-oriented approach.	✓ Reduction in FI, continent episodes and use of toilet for defaecation.
	• Review and documentation of resident history, normal bowel patterns using a person-centred framework.	• Residents’ previous history, preferences and patterns of elimination are known and included in care planning. • Family input.	• Continence care and planning is conceptualised and articulated by staff in terms of what is known about the person and what	✓ More dependent continence. ✓ Improved comfort and less distress for residents.

Interventions that reflect degree of cognitive and physical capacity of resident – personalised care planning.		• Residents' behaviours are considered in terms of how this reflects their understanding of how to, when and where they need to eliminate.	supports or inhibits their engagement with toileting and other interventions that support bowel health.	
	• Education to individualise giving of laxatives, enemas and manuals. • Structured input for residents. • Structured approach to care planning.	• Patient-centred care assessments. Care package of changes for each resident regarding diet, fluids, physical mobilisation, toileting, massage, attention to environment and use of laxatives/manual evacuation combined with nursing assessments.	• Staff more likely to act to promote bowel health.	✓ Reduced number of bowel-related interventions. ✓ Reduction in number of patients with constipation.
	• Visual cues for the toilet – in person's own room toilet left visible, in communal settings, 'toilet' label, picture of toilet and wayfinding arrows on floor.	• A setting where it is possible to implement these cues (floor arrows may not be possible in all settings). • A level of physical mobility in the individual to get to the toilet.	• Resident recognises where there is a toilet.	✓ More visits to the toilet room (this may then be a resource/context for appropriate use but additional resources or contexts will be needed to trigger that).
Establish a common understanding of the potential for recovery, reduction and management of FI for people with dementia.	• Education for staff that incontinence is not an inevitable part of dementia and ageing. • Person-centred care approaches across the care home.	• Use of assessment tools and referral to clinicians. • Review of residents' progress.	• Belief in the residents' potential to maintain or improve functional abilities even when the trajectory is one of deterioration.	✓ Staff engage and learn about what is causing the FI and attempt interventions to promote continence and the management of FI.
FI care integral to the everyday work pattern and	✓ 2-hourly toileting. ✓ Assistance with getting to the toilet and extra staff to support the intervention.	✓ Dementia is a risk factor for FI. ✓ PLWD need help to recognise or communicate their need to go to the toilet to defaecate. ✓ Residents' dementia/health, limits their mobility.	✓ Staff incorporate a routine of toileting into the residents' day and their work because they are routinely involved in providing regular physical care. ✓ Residents learn a routine.	✓ Continent bowel movements. ✓ Reduction in constipation.
	• Opportunity to talk to residents during personal care.	• Reinforced as invaluable opportunity to interact (within the time pressures).	• Time is made available to implement 'person-centred' approach to care.	✓ Tasks completed as quickly as possible.

environment of the care home.	• Training programme (in psychosocial interventions). • Care home routines. • Attachments between care staff and residents.	• Training teams promote the visibility of staff achievements and skills within the training. • Encouraged by management (plus peer support/cohesive team).	• A shared understanding about behaviours that challenge. • Triggers prioritisation of routines. • Status and importance of care assistant's work recognised among families, managers and commissioners. • Managers and commissioners believe in benefits of this approach to care and that it is possible to achieve change. • Triggers good relationships and empathy between staff and residents.	✓ Staff become focus on individual needs. ✓ All staff groups and family work together and communicate well about the care of the resident. ✓ Staff feel more valued. ✓ More resources committed to psychosocial interventions.

Source: Goodman et al. (2017)

Appendix 14: Participants information sheets

Staff Information Sheet – Phase 1
Short Title: ImFaCON Study
Study Title: Improving Faecal CONtinence among residents in care homes (ImFaCON): a feasibility study

Dear ________________________________

You are being invited to take part in a research study, which is seeking to improve faecal (bowel) continence among residents in care homes. The new intervention is known as ImFaCON (**Im**proving **Fa**ecal **CON**tinence). This leaflet explains why the research is being carried out and what it would involve for you. Please take time to read the following information carefully before you decide whether or not you would like to take part. We are happy to provide more information on anything you would like to know more about, and to answer questions if anything you read in this leaflet is not clear.

Thank you for taking your time to read this information leaflet. If you decide to take part in this study, you will be given a consent form to sign.

What is the study about?

This study will address bowel care within care homes by developing a new approach to continence care. This stage of the study is seeking staff views about what will work best for bowel care.

Who is undertaking this study?

This study is sponsored by King's College London and funded by the Abbeyfield Research Foundation. Mr Massirfufulay Musa (known as Maz), a student at King's College London is carrying out this research study in fulfilment of his Doctorate. Maz had worked in care homes as a Health Care Assistant prior to qualifying as a General Registered Nurse. This research study is supervised by three nurses: Professor Christine Norton (King's College London), Professor Ruth Harris (King's College London), and Professor Claire Goodman (University of Hertfordshire).

Why am I being invited to participate?

We want to talk with staff working with older people aged 65 years and above and living in care home whose job impacts residents' bowel management. The information you share with us will help to refine the intervention we are proposing.

Do I have to take part in this study?

No, participation is completely voluntary. If you do decide to take part in the study, you can withdraw from the study at any time without giving reasons for your decision. However, any information collected prior to you leaving the study shall form part of the final analysis of the study. Your decision either to participate or not, or to withdraw from the study shall in no way compromise your employment and other legal rights.

What will happen if I gave my agreement to take part?

You will be invited to attend either a focus group discussion, or a one-to-one interview. Each will last approximately one to two hours. At this meeting, we will be looking at some of the problems relating to faecal incontinence, and how these problems can be addressed taking into account your expertise of working with older people in a care home. We will use an encrypted audio recorder to help us capture all the information you will provide.

How will my data be used?

We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. King's College London will keep identifiable information about you for seven years after the study has finished. During this time, with your consent, we may re-use the data for other studies that have met ethics approval. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

King's College London (KCL) will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from KCL/ Guy's and St Thomas' NHS Foundation Trust and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in KCL who will have access to information that identifies you will be people who need to contact you to clarify a specific information or audit the data collection process. You can find out more about how we use your information KCL- www.kcl.ac.uk/innovation/research/support/ethics/how-does-gdpr-affect-ethics/king's-college-london-statement-on-use-of-personal-data-in-research.aspx

What are the potential benefits for taking part in this study?

By taking part in this study, you will be contributing to the development of a bowel care that may improve the way staff members working in care homes understand and care for older people with cognitive impairment when providing continence care.

Are there any risks to participants in this study?

No. We are not anticipate any risks.

Are there any financial incentives for taking part in this study?

No

Will my taking part in the study be kept confidential?

Yes. We will assign codes to you and any information you share with us during the study to keep your identity strictly confidential. The information we collect on audio will be kept in a secure location at KCL and we will transcribe the audio internally for analysis. With your permission, final report of this study may contain direct quotes from you, but we will not use your real name. Data will be securely stored on password-locked computers, accessible only by members of the study team. All information obtained during the study will be treated in accordance with the General Data Protection Regulation (GDPR) as incorporated in UK Data Protection Act 2018.

What will happen to the results of the study?

Results of this study will be used to help us develop bowel care intervention that we will be trying in the care home you work. The results will also be written as a thesis for a Doctorate at King's College London. On successful submission, the thesis will be available in the university's archives. The results will be fed back to your care home so that you can know the outcome. Results will also be disseminated locally, nationally and internationally through meetings, conferences, and publications in scientific journals.

Who has reviewed and approved this study?

This research study has been looked at by a group of people who are not involved in the project, called a Research Ethics Committee. These people are there to make sure that people like you taking part in a research study is safe and that your rights are respected.

Further information and contact details

If you would like further information, please contact:

1) Professor Christine Norton – Professor of Clinical Nursing Research
   King's College London, 57 Waterloo Road, London, SE1 8WA
   Telephone: 02078483864
   Email: Christine.norton@kcl.ac.uk

2) Mr Massirfufulay Musa – PhD Student
   King's College London, Room 1.32, 57 Waterloo Road, London, SE1 8WA
   Telephone: 07854009797
   Email: Massirfufulay.musa@kcl.ac.uk

Residents' Information Sheet – Phase 1

Short Title: ImFaCON Study

Study Title: Improving **Fa**ecal **CON**tinence among residents in care homes (ImFaCON): a feasibility study

Dear ________________________________

You are being invited to take part in a research study, which is seeking to improve faecal (bowel) continence among residents in care homes. The new intervention is known as ImFaCON (Improving Faecal CONtinence). This leaflet explains why the research is being carried out and what it would involve for you. Please take time to read the following information carefully before you decide whether or not you would like to take part. We are happy to provide more information on anything you would like to know more about, and to answer questions if anything you read in this leaflet is not clear.

Thank you for taking your time to read this information leaflet. If you decide to take part in this study, you will be given a consent form to sign.

What is the study about?

This study will address bowel care within care homes by developing a new approach to continence care. We want to talk with people who live in care homes about their experience of any bowel problems and what they feel might be helpful. This information will help us to refine the intervention we are proposing.

Who is undertaking this study?

This study is sponsored by King's College London and funded by the Abbeyfield Research Foundation. Mr Massirfufulay Musa (known as Maz), a student at King's College London is carrying out this research study in fulfilment of his Doctorate. Maz had worked in care homes as a Health Care Assistant prior to qualifying as a General Registered Nurse. This research study is supervised by three nurses: Professor Christine Norton (King's College London), Professor Ruth Harris (King's College London), and Professor Claire Goodman (University of Hertfordshire).

Why am I being invited to participate?

We are looking for people who are aged 65 years old or above, living in a care home (that is a Nursing Home or Residential Home), and having difficulties with managing their bowel. You will not be able to take part in the study if you have ostomy (colostomy or ileostomy), or if you do not live in a care home.

Do I have to take part in this study?

No, participation is completely voluntary. If you do decide to take part in the study, you can withdraw from the study at any time without giving reasons for your decision. However, any information collected prior to you leaving the study will form part of the final analysis of the study. Your decision either to participate or not, or to withdraw from the study shall in no way compromise your care.

What will happen if I gave my agreement to take part?

You will be invited to a single focus group discussion, or an interview. Each will last approximately one to two hours. At this meeting, we will be looking at some of the problems you have relating to the bowel, and how you wish to be supported and your ideas for improving bowel care. We will use an encrypted audio recorder to help us capture all the information you will provide.

How will my data be used?

We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. King's College London will keep identifiable information about you for seven years after the study has finished. During this time, with your consent, we may re-use the data for other studies that have met ethics approval. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

King's College London (KCL) will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from KCL/ Guy's and St Thomas' NHS Foundation Trust (GSTFT) and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in KCL who will have access to information that identifies you will be people who need to contact you to clarify a specific information or audit the data collection process. You can find out more about how we use your information KCL- www.kcl.ac.uk/innovation/research/support/ethics/how-does-gdpr-affect-ethics/king's-college-london-statement-on-use-of-personal-data-in-research.aspx

What are the potential benefits of taking part in this study?

By taking part in this study, you are contributing to the development of a bowel care that may improve the way staff understand and care for older people living in care homes with bowel incontinence.

Are there any risks to participants in this study?

Bowel care may be distressing to you, so there is a chance you may feel upset while discussing this topic. To minimise such distress, we will talk with you either in private, or along with your peers with a similar condition. We can postpone or stop the discussion at any time if you feel distressed.

Are there any financial incentives for taking part in this study?

No

Will my taking part in the study be kept confidential?

Yes. We will assign codes to any information you share with us during focus group meetings and interviews to keep your identity strictly confidential. With your permission, the final report of this study may contain direct quotes from you, but we will not use your real name. Data will be securely stored on password-locked computers, accessible only by members of the study team. All information obtained during the study will be treated in accordance with the General Data Protection Regulation (GDPR) as incorporated in UK Data Protection Act 2018.

What will happen to the results of the study?

Results of this study will be used to help us refine the bowel care intervention that we will be trying in your care home. The results will be written as a thesis for a Doctorate at King's College London. On successful submission, the thesis will be available in the university's archives. The results will be fed back to your care home so that you can know the outcome. Results will also be disseminated locally, nationally and internationally through meetings, conferences, and publications in scientific journals.

Who has reviewed and approved this study?

This research study has been looked at by a group of people who are not involved in the project, called a Research Ethics Committee. These people are there to make sure that people like you taking part in a research study is safe and that your rights are respected.

Further information and contact details

If you would like further information, please contact:

1) Professor Christine Norton – Professor of Clinical Nursing Research
King's College London, 57 Waterloo Road, London, SE1 8WA
Telephone: 02078483864
Email: Christine.norton@kcl.ac.uk

2) Mr Massirfufulay Musa – PhD Student
King's College London, Room 1.32, 57 Waterloo Road, London, SE1 8WA
Telephone: 07854009797
Email: Massirfufulay.musa@kcl.ac.uk

Relative Information Sheet – Phase 1

Short Title: ImFaCON Study

Study Title: **Im**proving **Fa**ecal **CON**tinence among residents in care homes (ImFaCON): a feasibility study

Dear ________________________________

We are carrying out a research study at the **Nightingale House Care Home** where your relative Mr/Mrs/Ms/Dr/Sir…………………………………………………resides. We would like to ask your opinion as a relative by inviting you to take part in the study.

We are planning to carry out a bowel care known as ImFaCON (**Im**proving **Fa**ecal **CON**tinence). This leaflet explains why the research is being carried out and what it would involve for you. Please take time to read the following information carefully before you decide whether or not you would like to take part. We are happy to provide more information on anything you would like to know more about, and to answer questions if anything you read in this leaflet is not clear.

Thank you for taking your time to read this information leaflet. If you decide to take part in this study, you will be given a consent form to sign.

What is the study about?

This study will address bowel care within care homes by developing a new approach to continence care. We want to talk with relatives of people who live in care homes about their knowledge of bowel problems in older people and what relatives feel might be helpful in caring for older people living in care homes with bowel problems. This information will help us to refine the intervention we are proposing.

Who is undertaking this study?

This study is sponsored by King's College London and funded by the Abbeyfield Research Foundation. Mr Massirfufulay Musa (known as Maz), a student at King's College London is carrying out this research project in fulfilment of his Doctorate. Maz had worked in care homes as a Health Care Assistant prior to qualifying as a General Registered Nurse. This research study is supervised by three nurses: Professor Christine Norton (King's College London), Professor Ruth Harris (King's College London), and Professor Claire Goodman (University of Hertfordshire).

What will happen if I give my agreement to take part?

You will be invited to attend either a focus group discussion, or a one-to-one interview. Each will last approximately one to two hours. At this meeting, we will be talking about some of the problems relating to bowel care and incontinence, and how these problems can be addressed taking into account your expertise. We will use an encrypted audio recorder to help us capture all the information you will provide.

Do I have to take part in this study?

No, participation is completely voluntary. If you do decide to take part in the study, you can withdraw from the study at any time without giving reasons for your decision. However, any information collected prior to you leaving the study shall form part of the final analysis of the study. Your decision either to participate or not, or to withdraw from the study will not compromise the care the care home provides for your relative.

How will my data be used?

We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. King's College London will keep identifiable information about you for seven years after the study has finished. During this time, with your consent, we may re-use the data for other studies that have met ethics approval. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

King's College London (KCL) will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from KCL/Guy's and St Thomas' NHS Foundation Trust and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in KCL who will have access to information that identifies you will be people who need to contact you to clarify a specific information or audit the data collection process. You can find out more about how we use your information

KCL- www.kcl.ac.uk/innovation/research/support/ethics/how-does-gdpr-affect-ethics/king's-college-london-statement-on-use-of-personal-data-in-research.aspx

What are the potential benefits for taking part in this study?

By taking part in this study, you will be contributing to the development of a bowel care that may improve the way staff members working in care homes understand and care for older people with cognitive impairment when providing continence care.

Are there any risks in taking part in this study?

No. We do not anticipate any risks.

Are there any financial incentives for taking part in this study?

No

Will my taking part in the study be kept confidential?

Yes. We will assign codes to you and any information you share with us during focus group meetings and interviews to keep your identity strictly confidential. The information we collect on audio will be kept in a secure location at KCL and we will transcribe the audio internally for analysis. With your permission, final report of this study may contain direct quotes from you, but we will not use your real name. Data will be securely stored on password-locked computers, accessible only by members of the study team. All information obtained during the study will be treated in accordance with the general Data Protection Regulation (GDPR) as incorporated in UK Data Protection Act 2018.

What will happen to the results of the study?

Results of this study will be used to help us refine the bowel care intervention that we are planning to carry out in the care home where your relative lives. The results will be written as a thesis for a Doctorate at King's College London. On successful submission, the thesis will be available in the university's archives. The results will be fed back to the care home so that you can know the outcome. Results will also be disseminated locally, nationally and internationally through meetings, conferences, and publications in scientific journals.

Who has reviewed and approved this study?

This research study has been looked at by a group of people who are not involved in the project, called a Research Ethics Committee. These people are there to make sure that people like you taking part in a research study is safe and that your rights are respected.

What happens now?

If you would like to take part in the study, you will be given this information sheet to keep and you will be asked to sign a consent form.

Further information and contact details

If you would like further information, please contact:

1) Professor Christine Norton – Professor of Clinical Nursing Research
   King's College London, 57 Waterloo Road, London, SE1 8WA
   Telephone: 02078483864
   Email: Christine.norton@kcl.ac.uk

2) Mr Massirfufulay Musa – PhD Student
   King's College London, Room 1.32, 57 Waterloo Road, London, SE1 8WA
   Telephone: 07854009797
   Email: Massirfufulay.musa@kcl.ac.uk

Appendix 15: Dementia friendly information sheet

Resident Accessible Information Sheet – Phase 2

Short Title: **ImFaCON Study**

Study Title: **Im**proving **Fa**ecal **CON**tinence among residents in care homes (ImFaCON): a feasibility study

Would you like to take part in some research?

By research we mean finding answers to questions that are important to you. You do not have to take part in the research.

Before deciding whether to take part, please read this leaflet or ask someone to help you read it.
It tells you what the research is about and what we would like you to do.

This research is about how to provide better care to older people living in care homes who have problems going to toilet, resulting in bowel accidents. We will call this faecal incontinence (or bowel problem).

We would like for you to try out the intervention we have developed.
It will require you or the staff looking after you to keep a diary of how often you go to toilet and the type of stool you pass. This will be done over 14 weeks. We will also ask you to complete some forms or tell us the answers to some questions to help us understand more about this problem.

The information we collect will help us to know whether our intervention worked or not.
When we are finished, we will inform you about the outcome of the research.

We will store the information we collect during the study on a computer. Don't worry, no one else have access to this computer, as it is password protected.

We will destroy the information we will collect after 7 years. During this time, with your permission we may re-use the information for other research studies.

If you are happy now to take part in the study please sign the Consent Form.

If you still need time to think about it we can meet you at another time.

King's College London is the sponsor for this research study.
We are separate from your care home.

If you would like further information, please feel free to contact us.

1) Professor Christine Norton – Professor of Clinical Nursing Research
   King's College London, 57 Waterloo Road, London, SE1 8WA
   Telephone: 02078483864
   Email: Christine.norton@kcl.ac.uk

2) Mr Massirfufulay Musa – PhD Student
   King's College London, Room 1.32, 57 Waterloo Road, London, SE1 8WA
   Telephone: 07854009797
   Email: Massirfufulay.musa@kcl.ac.uk

Appendix 16: Information sheet for consultees of residents

Consultee Information Sheet – Phase 2

Short Title: **ImFaCON Study**

Study Title: **Im**proving **Fa**ecal **CON**tinence among residents in care homes (ImFaCON): a feasibility study

Dear ________________________________

Mr/Ms/Dr/Sir…………………………………………………………………………….who is a resident of the **Nightingale House Care Home** has been invited to take part in a research study. We feel your relative/the person you represent is unable to decide for himself/herself whether to participate in this research. To help decide if he/she should join the study, we would like to ask your opinion whether or not he/she would want to be involved. We would ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide this person would have no objection to taking part, we will ask you to read and sign a consultee declaration form. We will give you a copy of the declaration form to keep. We will keep you fully informed during the study so you can let us know if you have any concerns, or you think this person should be withdrawn.

If you decide that your relative/the person you represent would not wish to take part, ***it will not affect the standard of care they receive in any way***. If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility. The following information is the same as would have been provided to your relative/the person you represent. Thank you for taking your time to read this information leaflet.

What is the study about?

This study will address bowel care within care homes by developing a new approach to continence care. We want people with faecal incontinence (bowel problems) who live in care homes to try out our proposed intervention that is intended to make them more continent.

Who is undertaking this study?

This study is sponsored by King's College London and funded by the Abbeyfield Research Foundation. Mr Massirfufulay Musa (known as Maz), a student at King's College London is carrying out this research study in fulfilment of his Doctorate. Maz had worked in care homes as a Health Care Assistant prior to qualifying as a General Registered Nurse. This research study is supervised by three nurses: Professor Christine Norton (King's College London), Professor Ruth Harris (King's College London), and Professor Claire Goodman (University of Hertfordshire).

What will happen if I give my agreement for this person to take part?

The study will last for 14 weeks. During this time, we will collect information about this person from a staff member who knows them well. We will ask them to tell us the frequency and consistency of the bowel motions of your relative/the person you represent. Depending on the condition of your relative/the person you represent, we may recommend a change of his/her diet or medication. We will write to their General Practitioner to help with any medication changes. A staff member will provide continence care and then makes entry in a bowel diary. We will provide two-weekly bowel diaries, total of 6 diaries over 14 weeks to be completed by staff working with your relative/the person you represent.

Does this person have to take part in this study?

No. It is up to you whether or not you want this person to take part in the study. You should only agree for the person to participate if you think they would like to take part. If you do not want the person to take part, or you want him/her to stop the study at any time this will not affect the care that he/she receives in any way. You do not have to give any reason for not wanting him/her to take part. However, once he/she enrolls in the study, any information we collect prior to your decision to withdraw him/her from the study will form part of the final analysis.

In case you are acting as a personal consultee and decide for the person you represent NOT to take part in the research study, please also contact a member of the research team using the contact details provided at the end of this leaflet. Please note that if you do not let us know of your decision as a personal consultee, this means that the research team (in collaboration with the Care Home) will nominate a consultee on behalf of your relative in accordance with the *Department Health 2008 guidance on nominating a consultee for research involving adults who lack capacity to consent*.

How will the data of my friend/the person I represent be used?

We will be using information from him/her in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after his/her information and using it properly. King's College London will keep identifiable information about him/her for seven years after the study has finished. During this time, with your consent, we may re-use the data for other studies that have met ethics approval. Your rights to access, change or move his/her information are limited, as we need to manage his/her information in specific ways in order for the research to be reliable and accurate. If you withdraw him/her from the study, we will keep the information about him/her that we have already obtained. To safeguard his/her rights, we will use the minimum personally identifiable information possible.

King's College London (KCL) will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from KCL/ Guy's and St Thomas' NHS Foundation Trust and regulatory organisations may look at his/her research records to check the accuracy of the research study. The only people in KCL who will have access to information that identifies him/her will be people who need to contact you to clarify a specific information or audit the data collection process. You can find out more about how we use his/her information at

KCL- www.kcl.ac.uk/innovation/research/support/ethics/how-does-gdpr-affect-ethics/king's-college-london-statement-on-use-of-personal-data-in-research.aspx

What are the potential benefits of participation?

By taking part in this study, this person is contributing to the development of an intervention that may improve the way staff care for and understand people with cognitive impairment when providing continence care. For some people, their bowel management may improve.

Are there any risks in taking part in this study?

We do not anticipate any risk for your relative/the person you represent, as we will be reviewing their care notes.

Are there any financial incentives for taking part in this study?

No

Will the identity of my relative/person I represent be kept confidential?

Yes. The person's confidentiality will be maintained. Personal data, such as name and date of birth will be kept separate from the information we collect. The person's anonymity will be maintained by being assigned an anonymised code which will be used throughout the analysis. The person will not be identified in any reports or academic papers coming from the work. All information collected during the study will be made anonymous and kept strictly confidential. The information given by staff members and through observed interactions between the person and staff will be stored securely, to enable researchers to continue analysis of the study data in future projects. However, in the unlikely event that we discover serious issues of concern regarding the person's wellbeing, we are required to break confidentiality and inform the medical or social care authorities.

Anonymous data may be shared with other researchers at King's College London (KCL) e.g., our collaborators and with researchers external to KCL. This is because of the recognition that publicly funded research is valuable and must be made available for secondary scientific research. This means that the important information we gather during our research can be used to answer other important research questions.

All information obtained during the study will be treated in accordance with the general Data Protection Regulation (GDPR) as incorporated in UK Data Protection Act 2018.

What will happen to the results of the study?

Results of this study will be used to improve bowel care in the care home where your relative/the person you represent lives. Results will also be written as a thesis for a Doctorate at King's College London. On successful submission, the thesis will be available in the university's archives. The results will be fed back to the care home so that you can know the outcome. Results will also be disseminated locally, nationally and internationally through meetings, conferences, and publications in scientific journals.

Who has reviewed and approved this study?

This research study has been looked at by a group of people who are not involved in the project, called a Research Ethics Committee. These people are there to make sure that people like your relative/the person you represent who is taking part in a research study is safe and that their rights are respected.

What if there is a problem during the study?

If you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions [Professor Christine Norton; Tel. 02078483864]. In the event that something does go wrong and the person you are representing is harmed during the research study then he/she may have grounds for legal action for compensation against King's College London, but he/she may have to pay his/her legal costs. King's College London maintains adequate insurance to cover any liabilities arising from the study.

Please be aware that if, during the course of the research, we become aware of an issue that poses a threat to the safety of residents, we will use our nursing experience and clinical judgement to decide if we need to report this matter to a senior person in the Care Home. This might in exceptional circumstances mean that we need to breach confidentiality.

What happens now?

If you believe that this person would like to take part you will be given this information sheet to keep and you will be asked to sign a consultee declaration form.

Further information and contact details

If you would like further information, please contact:

1) Professor Christine Norton – Professor of Clinical Nursing Research
King's College London, 57 Waterloo Road, London, SE1 8WA
Telephone: 02078483864
Email: Christine.norton@kcl.ac.uk

2) Mr Massirfufulay Musa – PhD Student
King's College London, Room 1.32, 57 Waterloo Road, London, SE1 8WA
Telephone: 07854009797
Email: Massirfufulay.musa@kcl.ac.uk

Appendix 17: Invitation letter to participants

Study Title: **Im**proving **Fa**ecal **CON**tinence among residents in care homes (ImFaCON): a feasibility study

Date: __________________________

Dear Mr/Ms/Mrs/Dr/Sir____

We kindly ask your participation in the above-mentioned research study. The research will be conducted in the **Nightingales House Care Home**. Details about the research, including what it is about, how it will benefit you, and what will be expected from you and from us (the research team) is contained in the information leaflet attached to this letter. Participation is completely voluntary. Please discuss this research with your partner, friends, or family.

Once you have read the information leaflet and decided to take part, please let a member of our research team know by calling telephone numbers __________________/__________________ to arrange a meeting where you can ask any questions on the information you have received.

We look forward to hearing from you.

Yours sincerely,

King’s College London Research Team
(ImFaCON Study)

Appendix 18: Research Ethics Approval

NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 1048 088

<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

21 May 2019

Professor Christine Norton
Florence Nightingale Professor of Clinical Nursing Research
King's College London
57 Waterloo Road
London
SE1 8WA

Dear Professor Norton

Study title:	**Improving faecal continence among residents in Care Homes: developing an intervention and conducting a feasibility study**
REC reference:	**19/YH/0089**
Protocol number:	**N/A**
IRAS project ID:	**244359**

Thank you for your submission of 07 May 2019, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable** ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non-registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor's Insurance certificate]	N/A	01 August 2018
GP/consultant information sheets or letters [GP LETTER (RESIDENTS WITH CAPACITY) PHASE 2]	1.0	12 December 2018
GP/consultant information sheets or letters [GP LETTER (RESIDENTS WITHOUT CAPACITY) PHASE 2]	1.1	09 April 2019
Interview schedules or topic guides for participants [Interview guide]	1.0	12 December 2018
Interview schedules or topic guides for participants [Focus group guide]	1.0	12 December 2018
Letter from funder [Funding letter]	N/A	29 July 2016
Letters of invitation to participant [Letter of Invitation Phase 1]	1.1	09 April 2019
Letters of invitation to participant [Reminder Letter of Invitation Phase 1]	1.1	09 April 2019

Letters of invitation to participant [Residents with Capacity and Care Staff Letter of Invitation Phase 2]	1.1	09 April 2019
Letters of invitation to participant [Residents with Capacity and Care Staff Reminder Letter of Invitation Phase 2]	1.1	09 April 2019
Letters of invitation to participant [Consultee Letter Phase 2]	1.1	09 April 2019
Letters of invitation to participant [Consultee Reminder Letter Phase 2]	1.1	09 April 2019
Other [Case Report Form]	1.0	12 December 2018
Other [Pre-screen checklist]	1.0	12 December 2018
Other [Proposed bowel diary]	1.0	12 December 2018
Other [SUPERVISOR'S CV - C. Goodman]	N/A	05 March 2019
Other [REC Provisional Opinion]	1.0	09 April 2019
Participant consent form [RELATIVE CONSENT FORM PHASE 1]	1.1	09 April 2019
Participant consent form [RESIDENTS CONSENT FORM PHASE 1]	1.1	09 April 2019
Participant consent form [STAFF CONSENT FORM PHASE 1]	1.1	09 April 2019
Participant consent form [CONSULTEE DECLARATION FORM PHASE 2]	1.1	09 April 2019
Participant consent form [DIRECT CARE STAFF CONSENT FORM PHASE 2]	1.1	09 April 2019
Participant consent form [RESIDENTS CONSENT FORM PHASE 2]	1.1	09 April 2019
Participant information sheet (PIS) [PIS RESIDENT ACCESSIBLE PHASE 1]	1.0	12 December 2018
Participant information sheet (PIS) [PIS STAFF INFORMATION PHASE 1]	1.0	12 December 2018
Participant information sheet (PIS) [PIS RESIDENTS PHASE 1]	1.0	12 December 2018
Participant information sheet (PIS) [PIS RELATIVES PHASE 1]	1.0	12 December 2018
Participant information sheet (PIS) [PIS RESIDENTS PHASE 2]	1.1	09 April 2019
Participant information sheet (PIS) [RESIDENTS ACCESSIBLE INFORMATION PHASE 2]	1.0	12 December 2018
Participant information sheet (PIS) [PIS CONSULTEE INFORMATION PHASE 2]	1.1	09 April 2019
Participant information sheet (PIS) [PIS DIRECT CARE STAFF PHASE 2]	1.1	09 April 2019
REC Application Form [REC_Form_25022019]		25 February 2019
Research protocol or project proposal [ImFaCON Protocol]	1.0	12 December 2018
Summary CV for Chief Investigator (CI) [CNorton CV]	N/A	03 January 2019
Summary CV for student [MMusa CV]	N/A	13 September 2018
Summary CV for supervisor (student research) [SUPERVISOR'S CV - R. Harris]	1.0	04 March 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/YH/0089 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours
sincerely pp

Sarah Prothero

Dr Janet Holt Chair

Email: nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Professor Reza Razavi*

Appendix 19: Focus group Discussion and Semi-structured interview Guides

Note: each question to be followed up with further prompts and explorations, with reference to the FINCH CMOs.

Focus Group Discussion Guide

1) Can you tell me what you know about bowel care and faecal incontinence?
    - Causes
    - Prognosis
    - Management
    - Inevitable
2) In your opinion, what might have contributed to FI in your relative/person you are responsible for?
    - Prompts: Correlates
3) Prior to your relative/person you are responsible for being admitted into care home, did he/she receive any support regarding FI? If so, can you describe who provided the care, and what type(s) of support was given?
4) What was the quality of life of your relative/person you are responsible for prior to his/her admission to the care home? How has this changed after admission?
5) Thinking about your relative/person you are responsible for, how exactly could care home staff support him/her in terms of bowel care?
6) Does your relative/person you are responsible for have memory problem? If so, what extra care support do you know that is currently available to him/her?
7) What do you think would improve bowel care and how could we measure this?

Semi-structure Interviews for Residents' Relatives

1) Can you tell me what you know about faecal incontinence?
    - Causes
    - Prognosis
    - Management
    - Inevitable
2) In your opinion, what might contribute to FI?
    - Correlates
3) Prior to your relative being admitted into care home, did he/she receive any support regarding FI? If so, can you describe who provided the care, and what type(s) of support was given?
4) On the scale of zero to ten, with zero meaning non-existent and ten meaning excellent, what was the quality of life of your relative prior to his/her admission to the care home?
5) Thinking about older people in general, how exactly could care home staff support them with bowel care?
6) Do you know any older person with a memory problem? If so, do you think he/she requires extra care support?
7) How may care home staff support a person with dementia with continence care?

Semi-structured Interviews for healthcare workers

1) Can you tell me what you know about faecal incontinence?
    - Causes
    - Prognosis
    - Management
    - Inevitable
    - Understanding of potential for recovery, reduction, and management of FI
2) In your opinion, what are some contributing factors for faecal incontinence?
    - Correlates
    - Current assessment for constipation
    - Management/treatment for constipation
3) What measures, if any, do you already have in place to address FI in your care home/unit?
    - Clinical lead support
    - Ongoing teaching of care staff
    - Dementia specific bowel management
4) What would be a clinically significant improvement in bowel management for your residents?
5) Can you name any benefit (s) that you foresee appropriate bowel management may lead to in your care home?

Semi-structured Interviews for Residents

1) Can you tell me what you know about faecal incontinence?
    - Causes
    - Prognosis
    - Management
    - Inevitable
2) In your opinion, do you think faecal incontinence is a problem to older people?
    - (If yes), is there anything that can be done to help a person with FI?
    - (If no), why do you say so?
3) Do you sometime experience problem in reaching to toilet to defecate on time?
   (If yes), what could be the reason for this?
   (As a follow on) – What help do you think staff can give you to overcome this problem?
4) In your opinion, what are some factors that contribute to FI in older people in general? (Specifically older people living in care homes?)
5) If you experience FI, what would be your expectation from staff helping you?
   Prompts to include:
    - ✓ Reduction in episodes of FI
    - ✓ Dignity
    - ✓ Respect for privacy

Appendix 20: Further consultation with stakeholders on areas for additional information

Programme theory 1

1) Do care staff have permission to carry out physical examination of a resident that is at risk of constipation or FI? What happens when you think a resident is constipated? What can you do, is there anything that you have to ask others to do?

a) If not, who might do this and how is it requested?

How and what do you do as a physical exam? If not, who could you call on to do this if you felt it was needed? What might make you think an exam was needed?

   a) If yes, how?
   b) If no, why not?
   c) Who gives 'permission'? (Find out if this is by policy, job description, senior staff, etc.)
      N/B: explore digital rectal examination

2) How could collaborative work with GPs (and Continence Lead) help improve your practice? (HCA/RN) Or how do you work together now and what might make it better?
   N/B: look for "confidence", "motivation", "shared communication", and "review of residents at risk".
3) There is a theory that 'ongoing support' by clinical lead (e.g. GP or Continence nurse specialist) for care home staff is important. Is this true in practice where you work?

   a) If so, how is this important in bowel care? What sort of support do you get and what else might help you and your residents?

   b) Who does it benefit and how does it benefit?

Programme theory 2

1) What is key to helping care staff improve continence care in practice?
   a) Is it training, or education?
   b) Why do you say so?
2) What specific training/education would be appropriate for staff to feel 'empowered' to improve continence care?
3) In your experience, what do you think would be a resource for staff carrying out continence care? What helps you, what do you use, or who do you ask?
   a) Is it getting on-going feedback from senior staff?
   b) Is it annual/biannual refresher training?
4) There is a theory that giving staff access to the appropriate training, education and facilitation will result in a change in practice.
   a) How true us that in practice?
   b) Can such change in practice results in reduction of frequency of FI episodes in people with dementia? If not, why not? If so, why and how?

    c) In your practice, what bowel care training have you had in practice and how did that help you in how you care for residents?

Programme theory 3

1) What can help staff to focus on recognising, treating and/or managing constipation?
    a) How do they recognise it?
    b) How is it treated or managed by staff?
2) What is your role in reducing or preventing risk of constipation to residents in your care?
   N/B: Look for the following
    - ✓ Providing balance diet and fluid to residents
    - ✓ Mobilising residents
    - ✓ Engaging residents in exercises (activities)
    - ✓ Communicating with residents (where possible) to uncover problems
    - ✓ Use of bowel, food and fluid charts
    - ✓ Regular vs scheduled toileting
    - ✓ Review of residents' medication (e.g., effects of laxatives and/or polypharmacy)
3) Evidence suggests correlation between constipation and FI. In your experience, how true is this? Can proper constipation treatment translate to reduction in FI among older people with dementia?
    a) If yes, why do you say so?
    b) If no, why not?

Programme theory 4

1) Can you always tell (or be able to draw conclusion from clues) that a resident with dementia needs toilet assistance?
    a) If yes, how?
    b) If not, why not?
       N/B: Probe respondent (s) for "familiarity with resident's characteristics and care needs".
2) In your practice, how regularly do you look at resident's charts (e.g., bowel, food, and fluid) when you provide care?
    a) And how do individual charts help to inform the care you provide?
    b) Can you describe any scenario in which you have looked at a resident's chart and how the information you gathered help you to care for him/her?
3) Can you describe the working relationship among HCAs, RNs, GP, etc. in terms of bowel care?
    a) Is there a hierarchy in terms of how one gets involved in bowel care?
    b) If so, how does that impact on resident's outcome (e.g., reduction in FI)?
    c) If not, can you describe how interprofessional collaboration in the care home can bring about good bowel care?

4) Do you always incorporate resident's preference/choice/wishes into his/her care (including bowel care)?
    a) If so, how do you do it taking into consideration other activities going on in the care home?
    b) If not, why not?
5) Is there a form of routine in this care home (e.g., around mealtimes and activities)? Generally, how do you incorporate "routine activities" into person-centred care?
6) Thinking about personal care and FI, how important do you think this is relevant? Can anyone really be able to provide this kind of work?
7) Considering this is a Jewish care home, does the Jewish culture have anything to do with how the care home is run?

Programme theory 5

1) Is it possible for a resident living with dementia to stop opening bowel in places that are inappropriate?
    a) If so, what can staff do to help such resident?
    b) If not, why not?
    N/B: This question aims to unravel nihilistic thinking around nothing can be done to help older person experiencing FI and living with dementia/cognitive impairment.
2) There is a theory that FI in people living with cognitive impairment such as dementia can be improved.
    a) In your experience, how true is that theory?
    b) If you agree, can you tell me why you think this is possible? If you disagree, why do you think it is not possible?
3) How does dementia affect a person's ability to participate in continence care?

Programme theory 6

1) What are some necessary conditions/things that need to be in place at the care home to make staff work towards improving FI in people living with dementia?
    N/B: This question is meant to teased out contextual factors.

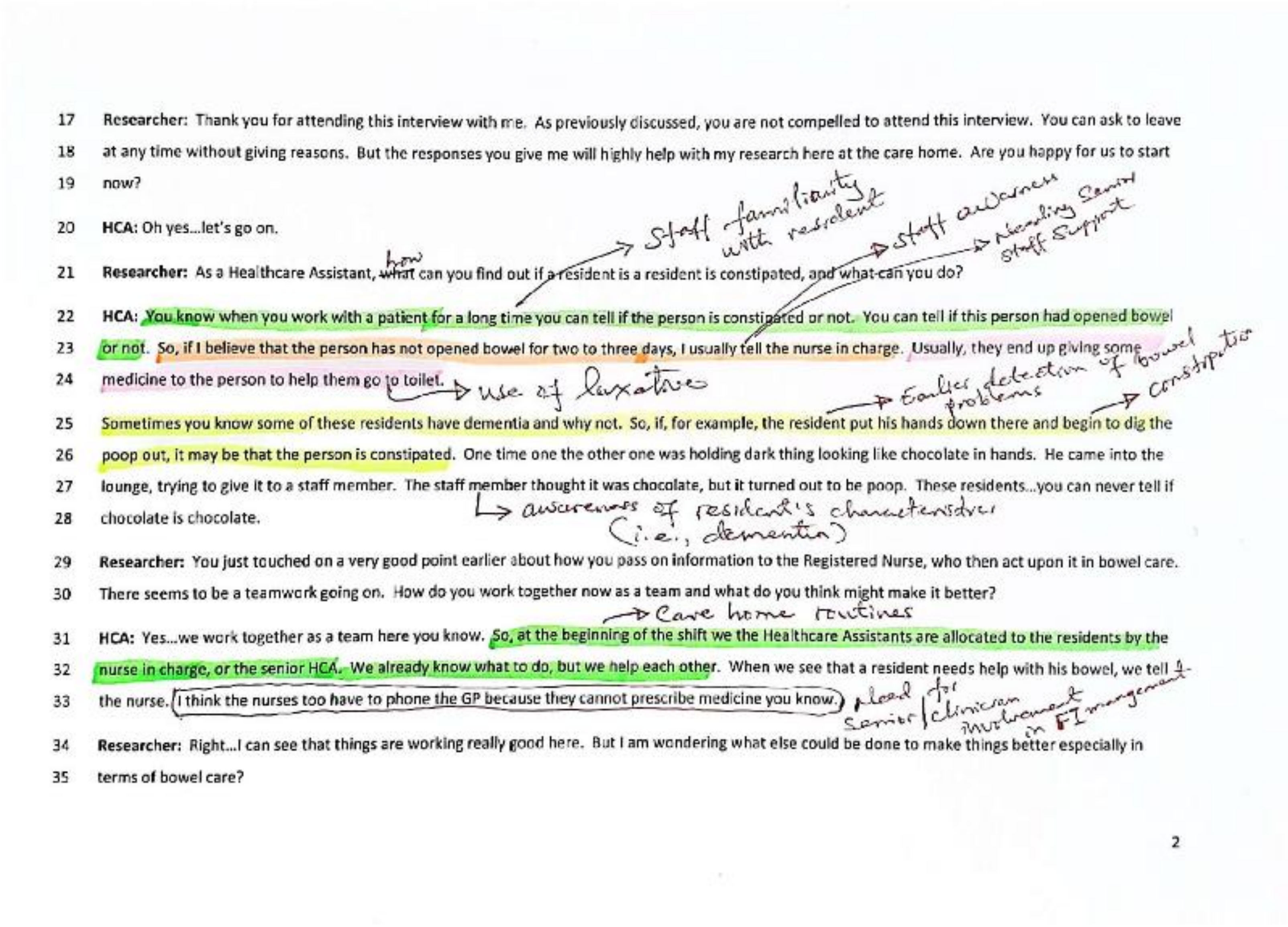
Intervention components – aimed at resident outcomes.

What programme will work, for whom and why? Ask about their opinions of what sort of residents/bowel issues might respond to:

i) Toilet exercises (scheduled or prompted toileting)
ii) Physical exercises (mobilising/ambulating residents)
iii) Conservative management (diet and fluid intake; review of medication – effects of laxatives and polypharmacy)

What other outcomes stakeholders consider to be viable in continence care?
What do they feel is a good outcome, and how realistic they feel that is for their residents living with dementia? What does good bowel care look like?

Appendix 21: Example of how scripts were coded



Researcher: Thank you for attending this interview with me. As previously discussed, you are not compelled to attend this interview. You can ask to leave at any time without giving reasons. But the responses you give me will highly help with my research here at the care home. Are you happy for us to start now?

HCA: Oh yes...let's go on.

Researcher: As a Healthcare Assistant, ~~what~~ how can you find out if ~~a~~ resident is a resident is constipated, and ~~what can~~ you do?

→ Staff familiarity with resident

→ Staff awareness

→ Needing Senior Staff Support

HCA: You know when you work with a patient for a long time you can tell if the person is constipated or not. You can tell if this person had opened bowel or not. So, if I believe that the person has not opened bowel for two to three days, I usually tell the nurse in charge. Usually, they end up giving some medicine to the person to help them go to toilet. → use of laxatives

→ Earlier detection of bowel problems

→ constipation

Sometimes you know some of these residents have dementia and why not. So, if, for example, the resident put his hands down there and begin to dig the poop out, it may be that the person is constipated. One time one the other one was holding dark thing looking like chocolate in hands. He came into the lounge, trying to give it to a staff member. The staff member thought it was chocolate, but it turned out to be poop. These residents...you can never tell if chocolate is chocolate.

→ awareness of resident's characteristics (i.e., dementia)

Researcher: You just touched on a very good point earlier about how you pass on information to the Registered Nurse, who then act upon it in bowel care. There seems to be a teamwork going on. How do you work together now as a team and what do you think might make it better?

→ Care home routines

HCA: Yes...we work together as a team here you know. So, at the beginning of the shift we the Healthcare Assistants are allocated to the residents by the nurse in charge, or the senior HCA. We already know what to do, but we help each other. When we see that a resident needs help with his bowel, we tell the the nurse. I think the nurses too have to phone the GP because they cannot prescribe medicine you know.

Need for Senior / clinician involvement in FI management

Researcher: Right...I can see that things are working really good here. But I am wondering what else could be done to make things better especially in terms of bowel care?

2

belief about FI + dementia

workload | Staffing issues

HCA: Hahahaha...do you think there is anything we can be done to make bowel care better? I really don't think so because when someone has dementia it is like uphill battle. You struggle to know if the person is in pain, needs help to go to the toilet, and why not. Maybe enough staffing because many days we have agency staff here. While that is good because they can help with some problems, it can be difficult for the regular staff because show them how to do things and that can be hard. So, we need many staff maybe that way we can do better in bowel care.

care home routine

Staffing Issues

Researcher: In your experience, what helps you as a Care Assistant to improve your job generally, and specifically in bowel care?

familiarity with resident's needs

HCA: Generally,.... well, let me say I like to know what I am doing, or supposed to do for a particular resident. So, it helps if I know the resident I am working with, or if I am given the time to read and familiarise myself with the resident's care plan. But you know...for the care home setting that is like Utopia. We are always short staffed and that can make the shift a hell. For bowel care, it helps if the resident is able to walk to the toilet and the resident is compliant. You know some of these residents, even when they walk to the toilet they just stand there, and you can't force them to go to toilet. So, dementia has huge impact on continence. It helps if the staff know what time the resident usually open bowel. In that way we can always be around that time to either take the resident to toilet, or to check the resident if he has already opened bowel. Also, we don't get specific training in bowel care. We do have training in other care areas that overlaps bowel care but it will be useful to have a mandatory bowel care training as part of staff inducting since the majority of our job as Care Assistant is taking residents to toilet and helping them with hygiene needs.

dementia + FI

understanding of PCC

Incorporating bowel care in routine care

common language understanding

Need for training

Researcher: Than you for that response. Let me now take you to another topic area: Can you always tell if a resident needs to go to toilet? I am saying this because I have been made aware of a resident that likes to smear faeces in his room. What could be the reason for this?

HCA: Like I said before, dementia is bad. No mature person in their rightful mind can smear faeces if that person hasn't got problem with their brain. It is hard sometimes to tell either because we are busy carrying out other tasks, or we completely miss the cue. For those residents with good history from family, we can sometimes tell if they want to use the toilet or not because it is in their care plans. The one that smears faeces is a difficult resident. When he shouts and you don't get there on time it will be everywhere!

On-going Staff Support

Need for proper assessment prior to care home admission

Appendix 22: Example of how the themes from FGD and interviews data were aligned with FINCH programme theories

Programme theory-1: Clinician-led support, assessment, and review

Subordinate themes	GP on site Clinician involvement in assessment Routine review of charts/residents Detection of bowel problems Continence lead	**MP2:** *"We have the incontinence lead now in each unit that we will be having a meeting…. For residents who are experiencing faecal incontinence, with an underlying cognitive impairment, we'd not be able to stop that due to their conditions …"* [FGD] **Respondent-1:** *"At the moment we have Continence Leads in the household, but most of the time what they do is to carry out assessments for the residents. For example, incontinence pads that we use. That is what they do most of the time. We don't have any training from them"*. [Group Interview-2: Staff] **FP4:** *"So, each unit has its own GP, so they get a visit once a week from their GP. So, any routine reviews would be referred … if I notice, for example, that someone has been omitting their laxatives for 2 or 3 weeks due to loose bowels, sometimes that does happen, I do flag up saying I think probably this needs to be reviewed."* [FGD] **MP1:** *"we can always refer to the GP or to our ANP. They will come to review and then we continue monitoring how the person goes."* [FGD] **Respondent-2:** *"We are not…well I am trained to do it [rectal examination], but we are not allowed to do it here. We have the advanced nurse practitioners who are allowed to do those things. …when I started working here even when I was working in another care home, we were advised not to do any digital rectal examination. So that might be according to the law."* [Group Interview-2: Staff]

Programme theory 2: Ongoing teaching, review, and feedback to care staff to reduce and manage FI		
Subordinate themes	Common understanding Staff awareness Staff motivation Staff confidence Staff training Need for staff support/feedback	**MP1:** *"sometimes when a new person comes in we inform them that if the residents will not open bowels for three days we have to as nurses refer to the doctor because they might be constipated. So, I'm not saying all the time that's happening, but we try also during the induction to remind the staff that already working and have experience here to tell the new staff."* [FGD] **RN:** *"We are expecting a continence nurse to come and give training to all the staff and then from there we would be having a meeting for all the leads to ensure that we are providing good equipment and then we, because those unit where they've got a resident with a little cognition then they can do toileting regime, taking them to the toilet, see if it can improve their incontinence like not using and sitting on the wet pad. But that would be after training with the incontinence nurse."* [Individual interview] **HCA:** *"We don't get specific training in bowel care. We do have training in other care areas that overlaps bowel care, but it will be useful to have a mandatory bowel care training as part of staff inducting since the majority of our job as Care Assistant is taking residents to toilet and helping them with hygiene needs…"* [Individual Interview] **HCA:** *"I have had bowel care training in the past. I was shown a video demonstrating how to clean the bum of a doll. But that was long time ago now. I think most people just assume that everybody knows how to clean bum…. If we have new staff, we can shadow them for few weeks just to make them get used to doing the job. Apart from that we don't really attend bum cleaning training."* [Individual Interview] **Respondent-2***: "I think it is more about educating people. You train them, you educate them. To improve the care. It is all about communication and educating people."* [Group Interview-2: Staff]

Programme theory 3: Addressing the causes and prevention of constipation		
Subordinate themes	Constipation as a bowel problem Earlier detection of bowel problems Fluid intake Use of laxatives How staff monitor bowel movement Management of constipation Lack of knowledge on constipation Understanding causes of constipation Nursing assessment for constipation	**HCA:** "*In the nursing home constipation for the elderly is quite high because with dementia they tend to forget things they are supposed to do. They're not drinking much unless you push the fluid. They need to eat healthy diet, balanced diet...more fruit to help go to the toilet" [Individual Interview]* **FP1**: *"They can have constipation or just find it very hard to go even if it's not constipation. So they have to have something to help them to go, which makes it easier and softer."* [Group Interview-1: Relative] **MP3:** *"As carers we recognise the signs of constipation very easily in our unit. So, if you see somebody is more disorientated than usual, if there is no urine infection or chest infection it should be the bowel and like 60% of the time when you do a referral it's come out as they were just constipated."* [FGD] **HCA:** *"If I think that my resident is constipated, I will encourage him/her to drink plenty of water. Because they always say water can help. I will let the nurse in charge know about it because only them can give out medicine, you know."* [Individual Interview] **FP5**: *"There are a number of factors we would consider if a person is constipated, one of them being if they are already on laxatives and if they are at risk of malnutrition and dehydration."* [FGD]

Programme theory 4: Interventions that reflect the degree of cognitive and physical capacity of the resident		
Subordinate themes	Assessment and history taking Person-centred approach Relying on own instinct Reducing distress Improve dignity Person-centred approach Familiarity with the resident	**FP9:** *"We always assess the residents when they first come in or their functional ability changes. When we've review them, if there's no change to their baseline then we will put some adaptations in place in their environment, in their toilet, and making sure the rails are in place, make sure they're safe and also raise the toilet to an appropriate height so they're actually off easily and to give them as good of a posture as possible so they can actually open their bowels much more easily"* [FGD] **HCA:** *"For those residents with good history from family, we can sometimes tell if they want to use the toilet or not because it is in their care plans." [Individual Interview]* **RN:** *"...we don't treat them in general, although they have got dementia, but we treat them [as] individual"* [Individual Interview] **MP4:** *Because staff they can read body language, they can see, there are certain things that they learn and say OK that means this person now needs to use the toilet."* [FGD] **R2:** *"In order to support our residents you need to know them. You need to know their life history from care plan; talk with family... Some of the questions we have to get answers from the relatives. The residents state of dementia means they won't be able to answer. This information starts from assessment and continues as long as the resident is living in the care home."* [Group Interview-2: Staff]

Programme theory 5: Common understanding of the potential for recovery and reduction of FI		
Subordinate themes	Causes of FI Believes episodes of FI can reduced with intervention Awareness of resident’s characteristics (e.g., dementia) Resident’s response to care Giving care dementia resident is challenging Appropriate toileting Management of FI/loose stool Staff recognise and support resident with FI	**FP5:** *“It is very much diet related. During that period of time [Passover] you remove a certain group of foods…anything that rises, anything with yeast, so all forms of cakes, breads, even pasta is removed because when you cook it it expands. You also have an ample supply of crackers…”* [FGD] **Respondent-1:** *“Say for example, when a resident need to go to the toilet, …if one is mobile, I’ve seen this one, he keeps pacing around saying that he has to go somewhere but he can’t say where.”* [Group Interview-2: Staff] **FP1:** *"Well you can again [reduce episodes of FI] with diet and medication review, I don’t know about in all cases but some cases.” [GFD]* **MP1:** *We can recognise signs even when they don’t have capacity. So when we see a movement or something we understand that, ah maybe they want to go to the toilet. And we assist the person. I think this generally is not just in our unit but we can see signs generally.”* [FGD] **HCA:** “When we see that a resident needs help with his bowel, we tell the nurse. I think the nurses too have to phone the GP because they cannot prescribe medicine you know.” [Individual interview]

Programme theory 6: Integrating care for people living with dementia and FI into everyday work patterns		
Subordinate themes	Care routines How dementia impacts continence How staff support residents with dementia What is considered normal bowel movement Importance of regular bowel movement Importance of bowel care (residents' and staff benefits) Dilemma in caring FI/dementia resident	**FP3:** *"Then it's a routine as well like after breakfast they attend activities, so between 11.00am to 11.30am just to use the towel just to see that they are dried; wash their hands and then get them to the tables. Then in the afternoon it's after teatime or prior teatime, and then after supper."* [FGD] **FP7:** *"I think it's the memory especially on our unit. Cognition. Some of them just don't have the control. Sometimes some underlying illnesses they feel like going, going, they have pain or it's not coming, like they just have the urge to go, that might be an illness or something but mostly it's the cognition."* [FGD] **FP9:** *"With the advanced dementia, sometimes with some residents they can be faecally incontinence if residents don't want that personal care, that sort of can be the dignity, it's a very private area. So that could be quite challenging and that could result in incontinence. I think we've had some residents that are refusing and not wanting and it's becoming quite a challenge."* [FGD] RN: *"If you don't manage the incontinence properly there will be other problems that will occur like a pressure sore."* [Individual Interview] **MP1:** *"the hardest part is when the residents are fighting back during personal care especially when they are big and strong. So there are staff that they are complaining that they are not feeling comfortable and sometimes we are not restricting anyone here but you have to be extra careful with these ones to support them even more. But you don't know that if you put more staff let's say to go to the toilet or with this resident if it will make it worse or if it will be."* [FGD]

Key: FGD = Focus Group Discussion; FP = Female participant; MP = Male participant; FI = Faecal incontinence

Appendix 23: Staff training/educational materials on bowel care for older people living with dementia in care homes

Outline:

LESSON ONE

OBJECTIVES: Staff knowledge – evidence-based information on managing FI (e.g., leaflets, brochures, and/or PowerPoint presentations).

- What is faecal incontinence?
- What causes faecal incontinence in older people?
- Prevalence of faecal incontinence among older people in the community?
- Prevalence of faecal incontinence in care homes?

EVALUATION: Staff attending training should write out their answers for the above questions prior to delivery of the learning materials (or them reading the learning materials) that follow.

LESSON TWO

OBJECTIVES: Staff attitudes – towards delivery of care (e.g., online or face-to-face training). Emphasis here will be on enabling staff to understand that bowel problems among older people living with dementia and FI is not an inevitable consequence of aging alone, but there may be other modifiable factors.

- Moving beyond nihilism in continence – Is faecal incontinence an inevitable health condition?
- Minimising “resistance-to-care” during assisted personal care for older people living with dementia in care homes. What are some challenges in providing personal care to a resident that resists staff support? How may staff resolve some of these challenges?

EVALUATION: Staff should have a five-minute opportunity to discuss the questions before delivery of the learning materials.

LESSON THREE

OBJECTIVES: Skills – ability to apply evidence-based information to individualised cases (e.g., online or face-to-face training). This information will cover materials in the training package, as well as the types of stools as described by the Bristol Stool Chart.
EVALUATION: skill-based questionnaires to make staff to put to reflect on the lesson learnt from the module.

LESSON ONE

What is faecal incontinence?

Faecal incontinence is the incapacity to appropriately control the bowel, resulting in leakage of faecal material which is a hygiene problem (Haylen et al., 2010, International Continence Society (ICS), 2020, Musa et al., 2019, Musa et al., 2018).
Depending on the mechanism of faecal incontinence, it may be described as: **faecal spillage** – the leakage of stool following normal evacuation; **passive incontinence** – an involuntary discharge of stool or gas without awareness; urge incontinence – discharge of faecal matter despite attempts to retain bowel contents; and **functional incontinence** – a voluntary incontinence due to functional limitation and/or agronomic barriers (Jerez-Roig et al., 2015, Rao and American College of Gastroenterology Practice Parameters, 2004).

Faecal incontinence is a sign or symptom, rather than a diagnosis (National Institute for Health and Care Excellence (NICE), 2007b). There are many conditions that have correlations with FI, some of which are modifiable (e.g., diet, poly-pharmacology, inadequate resources, and dysfunctional work culture, etc.) and others are non-modifiable (e.g., dementia, Parkinson disease, stroke, spinal injuries, diabetes, vision impairment, frailty, limited access to toileting assistance, etc.) (Table 1). Therefore, it is important to diagnose the underlying cause of faecal incontinence for individuals to manage the faecal incontinence condition most effectively (National Institute for Health and Care Excellence (NICE), 2007b).

Table 1: Risk factor of faecal incontinence

Description	Examples
Neurological factors	❖ Dementia ❖ Parkinson's disease ❖ Multiple sclerosis ❖ Stroke ❖ Diabetic mellitus ❖ Spinal bifida ❖ Pudendal neuropathy (Alcock canal syndrome)
Faecal impaction with overflow	❖ Low fibre diet ❖ Poor fluid intake ❖ Immobility ❖ Medications such as Codeine phosphate, opioids
Anal sphincter damage, weakness or degeneration	❖ Obstetric trauma: instrumental delivery, large baby ❖ Post-surgery: anal stretching, haemorrhoidectomy ❖ Direct trauma ❖ Radiotherapy for cervical or pelvic neoplasm
Diarrhoea and intestinal injury	❖ Ulcerative colitis ❖ Crohn's disease ❖ Irritable bowel syndrome
Environmental factors	❖ Ability to reach toilet in time ❖ Access to toilet facilities ❖ Laxative induced or side effects of medication
Congenital	❖ Imperforate anus ❖ Cloacal defects ❖ Rectal agenesis ❖ Myelomeningocele
Anorectal pathology	❖ Rectal prolapse ❖ Anal fistula or fissure ❖ Cancer

Source: (Adegbola and Donnelly, 2010)

How widespread is faecal incontinence in adult population in general?

The true prevalence of faecal incontinence in the adult population is unknown due to methodological differences in how research on the topic is carried out. However, evidence suggests that the prevalence rate of faecal incontinence could range between 0.004% to 20.7% (Blekken et al., 2016, Ihnat et al., 2016, Melzer et al., 2015, Ng et al., 2015, Sharma et al., 2016).

How widespread is faecal incontinence among older people living in care homes?

The true prevalence of faecal incontinence among care home residents worldwide is unknown (Madoff et al., 2004). The reasons for dearth of knowledge about faecal incontinence include under-reporting of symptoms by patients, lack of knowledge among healthcare workers about treatment options, and disagreement on faecal incontinence definition. However, care home-based studies have reported estimates of faecal incontinence prevalence ranging from 6% to 54% (Blekken et al., 2016, Tobin and Brocklehurst, 1986). In one recent systematic review, it was found that medians for prevalence (as reported by the studies) of isolated faecal incontinence, double incontinence, and all faecal incontinence were 3.5% [interquartile range (IQR) ¼ 2.8%], 47.1% (IQR ¼ 32.1%), and 42.8% (IQR ¼ 21.1%), respectively (Musa et al., 2019).

LESSON TWO

Moving beyond nihilism in continence – Is faecal incontinence an inevitable health condition?

Faecal incontinence remains a taboo subject despite its recognition more than a decade ago (National Institute for Health and Care Excellence (NICE), 2007a, Norton, 2004). There is usually a multifactorial interacting risk of faecal incontinence among frail, elderly people that include age-related physiological changes, multiple pharmacological treatments, comorbidity and cognitive decline (Musa et al., 2019).

Opportunities to assess, treat and reduce the number of incontinent people are being missed (Wagg et al., 2005). In 2012, a care home continence audit carried out in the UK identified ageism, lack of staff training, restrictions of pad usage because of cost control and poorly integrated services as contributory factors for low standards of care for faecal incontinence (Harari et al., 2014).

Minimising “resistance-to-care” during assisted personal care for older people living with dementia in care homes.

Many older adults with dementia live in care homes and most of them require assistance with personal care due to having dementia-related symptoms. Care staff frequently experience resistance or rejection from such residents when they are providing care (Ishii et al., 2012, Morgan et al., 2012).

Resistance-to-care means physically and/or psychologically resistive behaviour, for example pulling away from staff, tightening limbs, stiffening the body, deliberately ceasing or refusing to weight bear during care, waving arms and legs and verbally objecting to care using words and/or sounds (Ferrah et al., 2015).

Improved communication among staff and between staff and residents, as well as familiarisation with residents' care plan are key to ameliorating resistance to care by care home residents.

What should the care staff look out for in terms of bowel management when caring for care home residents, especially those with dementia?

1) Staff should familiarise themselves with residents' bowel movement pattern as per residents' bowel care plan.
2) Staff should know the types of stools as per the Bristol stool chart and know how to apply it to individual residents (Figure 7.3).
3) Staff should monitor residents' bowel charts and seek clinicians' assistance when bowel problems (e.g., constipation or diarrhoea) are noticed.

Appendix 24: Example of paper Case Report Form – Daily ImFaCON research activities monitoring chart

Date: _____ Resident's ID/Initials: _____________

Scheduled toileting	07:30-09:30		09:30-11:30		11:30-13:30		13:30-15:30		15:30-17:30		17:30-19:30		Comments
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	
Sit and Stand	07:30-09:30		09:30-11:30		11:30-13:30		13:30-15:30		15:30-17:30		17:30-19:30		Comments
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	
Between meals Snacks	First snack detail				Second snack detail				Third snack detail				Comments
Fluid intake	Water			Milk			Tea or coffee			others			Comments
07:30-09:30													
09:30-11:30													
11:30-13:30													
13:30-15:30													
15:30-17:30													
17:30:19:30													

Please add as much information as possible in the comment sections to avoid incomplete data entry. For example, if a resident is off the ward, please use the comment sections to say so.

Appendix 25: Staff knowledge and confidence level in bowel care

All staff please answer the questions below and return it. DO NOT WRITE YOUR NAME ON THIS PAPER.

DATE: ____________________ PARTICIPANT'S NUMBER: _________________

Questions	A	B	C
Part A			
Faecal incontinence can affect anyone.	False	True	Only old people
There are only two causes of faecal incontinence: advanced age and dementia.	Advanced age and dementia	Dementia is the only cause	There are many factors associated
Older people with dementia will always be incontinent of faeces.	True	False	I don't know
Faecal incontinence is an inevitable condition for older people.	True	False	I don't know
Older people living in the community are no different from older people living in care homes when it comes incontinence problems.	True	False	I don't know
There is nothing that you can do to stop someone with dementia to stop being incontinent of faeces.	True	False	I don't know
Knowing the underlying causes of faecal incontinence can help to reduce frequencies of episodes in some people.	True	False	I don't know
Constipation and diarrhoea can be managed among some older people living with dementia.	True	False	I don't know
To address constipation, it is good practice to keep good bowel diary.	True	False	I don't know
The only treatment for constipation is laxative (e.g., Senna, Laxido, etc.).	True	False	I don't know
Part B: *The third column has been left blank for you to provide answer in your own words if either A or B are not applicable to you.*			
I have never had bowel care training.	Somehow true	Not at all	
I am more confident in providing incontinence care to residents in my care.	Somehow true	Not at all	
I find people with dementia challenging when it comes to bowel care.	Somehow true	Not at all	
I do not need bowel care training.	Somehow true	Not at all	

Part C: *Please indicate in percent (%)*

1) Your knowledge about providing bowel care for older people living with dementia in care homes

______%

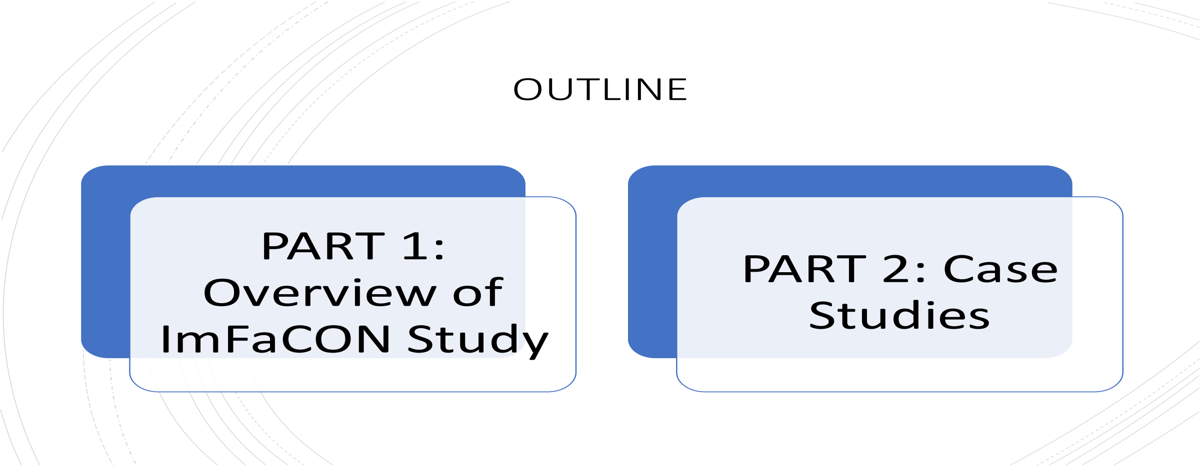
2) Your confidence level in providing bowel care to older people living with dementia in care homes

_______%

Appendix 26: Presentation to the care staff

InFaCONStudy

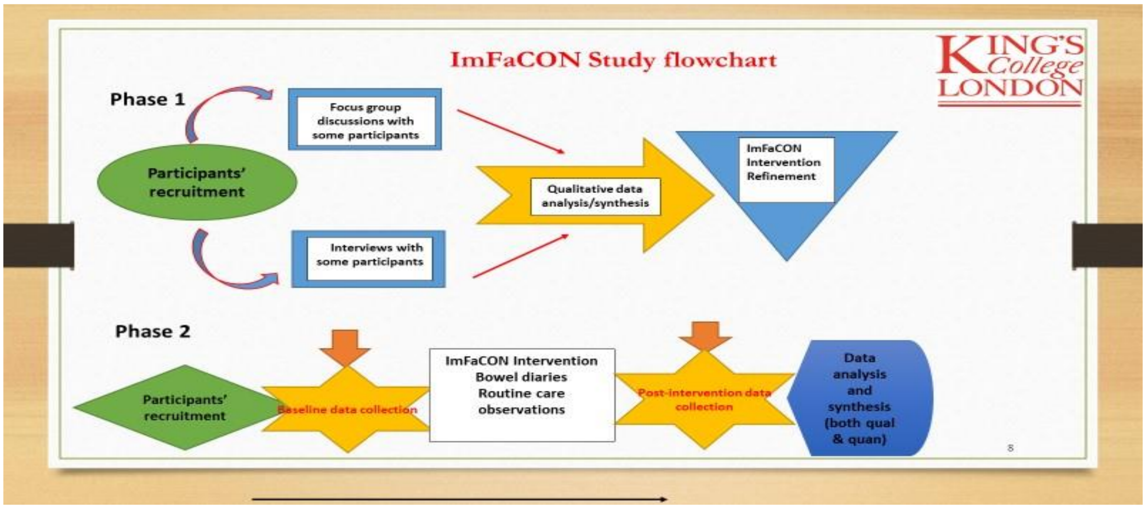
Maz Musa, PhD Student



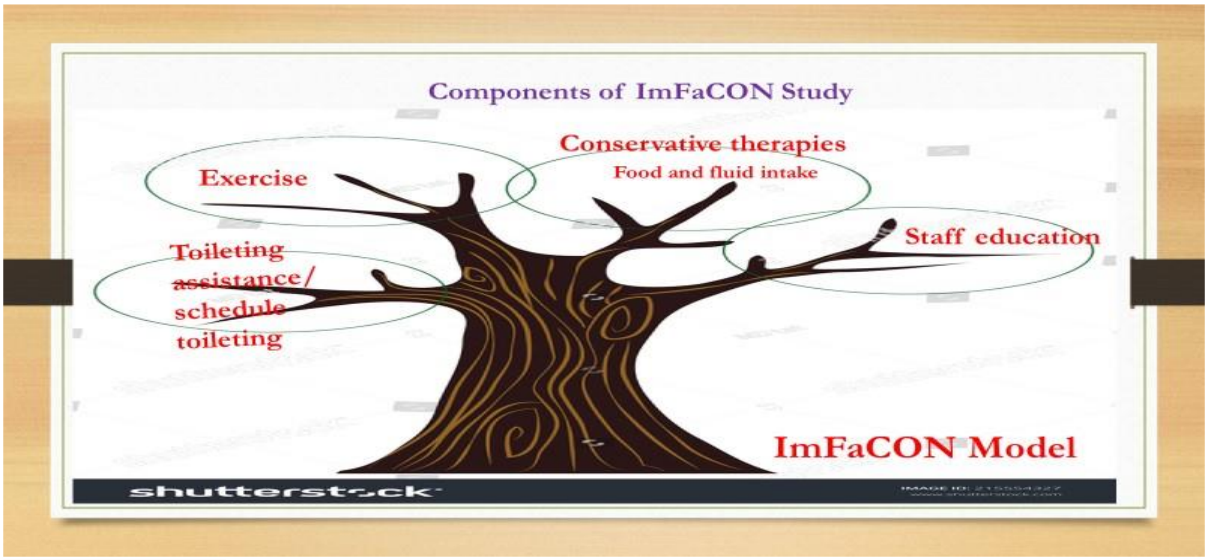
OUTLINE

PART 1: Overview of ImFaCON Study

PART 2: Case Studies



ImFaCON Study flowchart



Components of ImFaCON Study

Staff education

- Staff knowledge – factual information + theoretical concepts
- Attitudes – towards delivery of care
- Skills – ability to apply factual information to specific situation

How we aim to achieve this?

Staff training? Content?

Exercise– Functional Incidental Training (FIT)

- FIT: care processes that are designed to increase activity and functional ability which can be integrated with incontinence care.
  - Before or after incontinence care, staff encouraged residents to walk or, if non-ambulatory, to wheel their chairs and to repeat sit-to-stands up to eight times using the minimum level of human assistance possible.
  - Residents to be encouraged to exercise (repeat sit-to-stands and walking or wheelchair propulsion) for up to 5 minutes.
  - Residents nursed in bed to be given upper body resistance training (arm curls or arm raises).

Conservative therapies fluid + food intake

Before and after each care episode, staff offer liquid to residents.

Offering residents a choice of snacks and fluids several times per day between meals.

Toilet assistance– prompted/scheduled?

This is to be tailored to resident’s needs.

For further discussion by the care team.

PART 2: Case studies

Residents currently enrolled:

Group A: **1001**; 1002; 1002

Group B: 1004; 1005; 1006

Group C: 1007; 1008; 1009

Group D: **1010**; 1011; 1012

Thank You For Listening

Appendix 27: ImFaCON Study Manual to Support Care Home staff

Improving Faecal Continence (ImFaCON) study aims to reduce episodes of faecal incontinence among older people with dementia living in care homes.

To use this manual, users are advised to refer to the table below. The table provides useful tips to help staff when choosing a component of intervention that may be suitable for a resident. Making such a decision when caring for a care home resident is in line with person-centred care.

Table 1: ImFaCON algorithm

	YES	NO
Does the staff member feel confident in supporting a resident who experiences faecal incontinence and has underlying dementia?		Attend training session on bowel management
Is the resident mobile independently, or with staff support can the resident use commode?	Prompted toileting	Scheduled toileting
Is the resident restricted (e.g., wheelchair user, or bedbound)?	Scheduled toileting	prompted toileting
Do you know the bowel pattern of your resident from the resident's bowel diary and/or other documentations?	Prompted toileting	Scheduled toileting
Does the resident have a particular activity of interest?	Promote that activity	Engage low intensive physical exercise
Does the Malnutrition Universal Screening Tool (MUST) score for your resident indicate dehydration?	Increase fluid intake	
In between meals, is your residents having snacks that are rich in fibres?		Promote fibre intake
Is your resident experiencing constipation despite interventions?	Refer resident for clinical review	
Is your resident having non-infectious diarrhoea/loose stool?	Refer resident for medication review	
Is your resident having more than two medications, some of which are opioids, Antiparkinsonian drugs, Antiarrhythmics, or Iron supplements?	Refer resident for medication review	

ImFaCON Study will be delivered over 10 weeks through multiple case studies. During the first two weeks, the researcher will meet with care staff to map out which intervention works better for a resident based on the staff knowledge of working with that resident. Then the following 8 weeks will involve the interventions below.

Components of ImFaCON

There are five different but coordinated components of the ImFaCON study, all of which are conservative treatments. A conservative treatment is a type of treatment that is non-invasive (e.g., surgical procedures). Each component of the ImFaCON study is designed to be individualised to a resident's needs because every person is different. The components are:

- Toileting exercises
- Physical exercises
- Review of residents' care plan
- Dietary fibre and fluid intakes
- Staff training

Component 1: Toileting exercises

The aim of this component is to increase the number of continent bowel motions in the toilet or commode and ultimately to a reduction in episodes of faecal incontinence (FI). The staff need to collect resident's bowel history (if the resident is new to the care home, this history may come from family members, or the resident's previous carer) and record a bowel diary for at least a month. The bowel diary will help the care staff to observe patterns of a resident's bowel motion. Care staff then need to use the algorithm (Table 1) to determine whether this component of the intervention is appropriate or not for a resident.

3) ***Prompted toileting*** – depending on the bowel habit of a resident (e.g., frequency of bowel movement) and functional abilities (e.g., ability to mobilise to toilet), staff to prompt the resident to use the toilet (when he/she needs to according to their bowel diary and episodes of FI) during day shift (e.g., 07:30 to 19:30). This should be individualised in the resident's care plan. Evidence suggests that prompted-voiding is highly effective with urinary incontinence, (Siswoyo et al., 2021) but much less effective with FI. (Ouslander et al., 1996b, Schnelle et al., 2010, Simmons and Schnelle, 2004) For this reason, it is recommended for this component to be used in conjunction with other components as proposed herein. This type of intervention is consistent with recommendations made by national guidelines, (National Institute for Health and Care Excellence (NICE), 2007b, National Institute for Health and Care Excellence (NICE), 2014, National Institute for Health and Care Excellence (NICE), 2021) and international guidelines (Landefeld et al., 2008) on preventing FI.
4) ***Scheduled continence care*** – for resident that is nursed in bed, and/or for whom there are no apparent pattern of his/her bowel habits (regardless of functional abilities), continence care (e.g., staff checking continent pads and cleaning up a resident when he/she is incontinent at 2-hourly interval (**6 times daily)** or supporting him/her to use toilet at 2-hourly intervals (**6 times daily)** to avoid a moisture lesion or pressure ulcers due to FI. The use of incontinence pads between scheduled continence care is recommended to ensure comfort and/or dignity for the resident.

Component 2: Physical exercise

This component is to increase activity and functional ability of a resident, as well as improve colonic transit time (CTT). (Cho et al., 2013, Howard et al., 2008, Yurtdaş et al., 2020) The component is designed to help improve residents' mobility, thus leading to improved constipation through residents having regular bowel movements (using toilet facilities and/or commodes). It involves either walking, upper arm movements, or sit/stand activities (**6 times daily**) to be carried out by a resident. The choice of this component should be determined by staff based on the individual resident's characteristics (Table 1). It requires the care staff to do the following:

5) Staff to individualise exercise activities, e.g., some residents may be able and prefer to walk round the garden.
6) Before or after incontinence care, staff to encourage the resident to walk or, if non-ambulatory, to wheel his/her chair and to repeat sit-to-stands, **6 times** using the minimum level of human assistance possible. (Bates-Jensen et al., 2003)
7) Resident to be encouraged to exercise (repeat sit-to-stands and walking or wheelchair propulsion) for up to **5 minutes up to 6 times** during day shift (e.g., 07:30 to 19:30). (Bates-Jensen et al., 2003, Schnelle et al., 2010)
8) Resident nursed in bed to be given upper body resistance training (arm curls or arm raises) after every episode of continence care, or **6 times** during day shift (e.g., 07:30 to 19:30).
9)

Component 3: *Review of residents' care plan by a clinical lead*

This component ensures management of constipation, or loose stool which can sometimes be a precursor to FI. The component aims to promote management of bowel problems such as constipation and diarrhoea, and the choice of this component should be based on information like those in Table 1. This component involves a clinical lead (e.g., a nurse, pharmacist, or General Practitioner (GP)) reviewing residents' care plans at least once in 14 days to address problems associated with overuse of laxatives and/or polypharmacy, or drugs which causes constipation.(Goodman et al., 2017) A table below (Table 2) shows examples of medications that have been implicated in development of constipation. The 14 days period will help the reviewing clinician to look at the bowel pattern of the individual resident, considering whether the resident is experiencing constipation or over-use of laxatives. The time frame may also help the clinician to promptly take appropriate action such as referring the nurse or pharmacist referring a resident to his/her GP for help, or the resident's medication being changed or stopped by a GP. It must be emphasised that if a diarrhoea lasts for more than four weeks or comes and goes regularly over a long period of time and the problem is not resolved quickly, it may result to dehydration among very old people (many of whom have many comorbidities) and this could lead to serious complications of their health.

Table 2: Some medications associated with constipation

Broad names	Examples
Opioids	Codeine, Tramadol, Morphine, Oxycontin, Hydrocodone, Fentanyl, etc.
Nonsteroidal anti-inflammatory agents	Ibuprofen, high-dose aspirin, Naproxen, Diclofenac, etc.
Tricyclic antidepressants	Amitriptyline, Nortriptyline, Doxepin, etc.
Antiparkinsonian drugs	Levodopa, Dopamine, Amantadine, etc.
Antipsychotics or neuroleptics	Aripiprazole (Abilify), Clozapine, Olanzapine, Risperidone, etc.
Calcium channel blockers	Amlodipine, Diltiazem, Felodipine, Verapamil, etc.
Diuretics	Indapamide, Metolazone, etc.
Centrally acting antihypertensive drugs	Clonidine, Guanfacine, etc.
Iron supplements	Ferrous fumarate, Ferrous sulfate, and Ferrous gluconate
Calcium supplements	Calcium carbonate, Calcium gluconate, etc.
Beta-adrenoceptor antagonist	Bisoprolol, Atenolol, Nebivolol, Propranolol, etc.

Component 4: Dietary fibre and fluid intake

There is a common African saying that if one has problems with his/her bowel, he/she should be mindful of what goes in the mouth. In other words, the food that one eats affect his/her bowel in different forms (e.g., it may cause diarrhoea, or faecal impaction). While this view is anecdotal, there is also scientific evidence that suggests the need for fibre-rich diets and proper hydration to enable easier bowel movement. For older people with dementia living in care homes, the need for high fibre diet and increased fluid intake become even more important because many of them are often on soft diets due to difficulty in swallowing food, or they often cannot remember to drink.

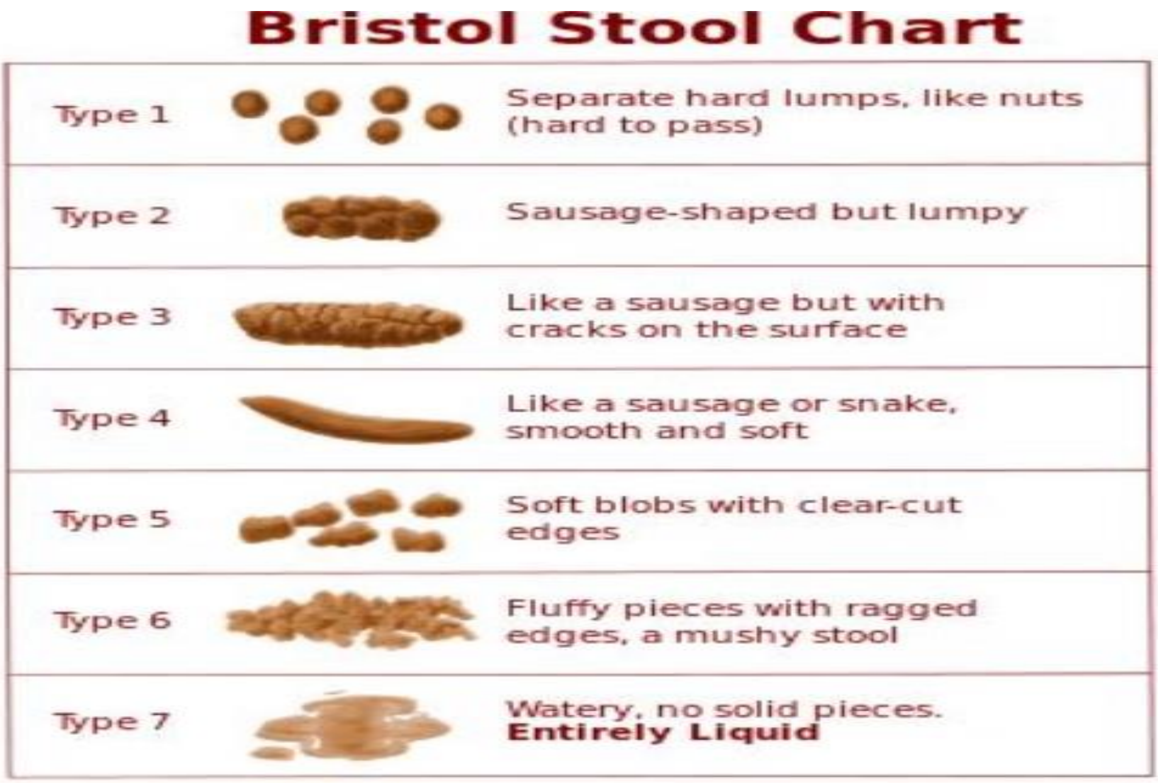
4) In between meals, staff to offer resident a choice of ***high fibre snacks*** three times per day between to increase fibre intake.(Schnelle et al., 2010) The recommended daily calorie intake is 2,000 calories a day for women and 2,500 for men.
5) In between meals, staff to verbally prompt and support a resident with a drink eight times per day to increase ***fluid intake.***(Simmons et al., 2001) The recommended amount of water per day for an adult is approximately 1600ml to 2000ml per day (or 6

to 8 cups or mugs, based on a 250ml mug). Women will require around 1600ml and men around 2000ml.

Component 5: Staff training

This component aims to serve as a resource for staff to either learn new skills or re-familiarise themselves with necessary information that may help them to confidently carry out bowel management. Every staff member should attend at least one training session which may be delivered ether online or face-to-face. Before every training session, staff members will be required to complete a questionnaire. The questionnaire is designed to gather baseline information. At the end of the research study activities, another set of questionnaires will be given to the same staff. The training and/or learning resources to cover:

4) Staff knowledge – evidence-based information on managing FI. The mode of delivery will be by way of a PowerPoint presentation by the researcher, accompanied by learning materials as resource for the staff.
5) Staff attitudes – towards delivery of care. The mode of delivery will be by PowerPoint presentation by the researcher, accompanied by learning materials as resource for the staff. This will help staff to appreciate that bowel problems among older people living with dementia (OPLD) and FI is not an inevitable consequence of aging alone, and that there may be other modifiable factors.
6) Skills – ability to apply evidence-based information to individualised case. The mode of delivery will be by PowerPoint presentation by the researcher, accompanied by learning materials as resource for the staff. Staff will be given the opportunity to apply the information they have learned in the form of case studies.



Bristol Stool Chart

Type 1	Separate hard lumps, like nuts (hard to pass)
Type 2	Sausage-shaped but lumpy
Type 3	Like a sausage but with cracks on the surface
Type 4	Like a sausage or snake, smooth and soft
Type 5	Soft blobs with clear-cut edges
Type 6	Fluffy pieces with ragged edges, a mushy stool
Type 7	Watery, no solid pieces. **Entirely Liquid**

How is the Bristol Stool chart used by ImFaCON?

Stool consistency	Frequencies of bowel movement per week
1-3: Constipation	≤ 3 episodes: Constipation
4 & 5: Normal stool	4/5 episodes: Normal
6 &7: Loose stool	> 5 episodes: may need intervention based on stool consistency

What is required for the research study?

- As a staff member, you need to be confident in your work. The ImFaCON Study is providing a one off 30-minutes training session specifically on bowel care. It will be helpful for you to attend this training session.

For the resident, you are required to do the following:

1. If a resident has been assessed as "scheduled toileting" or "prompted toileting" you are required to attend to that resident every 2 hours, **6 times daily** (07:30 to 19:30). For scheduled toileting, you are required to physically check the resident and to change incontinent pad if he/she is incontinent. For prompted toileting, you are required to prompt the resident and support him/her to the toilet, or on the commode. During each care contact with the resident, you are required to put an "X" for either Yes or NO in the research activities chart. For every "YES" please write below the X: **BO** for opened bowel, **PU** for passed urine, **DI** for double incontinence, or **C** for resident being continent. And for every NO, please below an "X" **RR** for resident refused or **AB** for resident being off the ward

   Please also make corresponding entry in person-centred care (PCC) app and indicate type of stool passed (if any). In the comment section of the research activities chart, please make any helpful remark as shown in the example below.

Scheduled Or Prompted toileting	07:30-09:30		09:30-11:30		11:30-13:30		13:30-15:30		15:30-17:30		17:30-19:30		**Comments**
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	
		X RR	X BO			X AB		X AB	X PU		X DI		e.g., 07:30 – 09:30 resident declined; 11:30 to 15:30 resident off the ward with relatives, etc.

2. If a resident has been assessed being capable of walking, doing upper arm movements, or sit/stand activities, staff members should support the resident to achieve the activity every 2 hours, **6 times daily** (07:30 to 19:30). During each care contact with the resident, you are required to mark "X" for either YES or NO in the research activities chart. In the comment section of the research activities chart, please make any helpful remark as shown in the example below.

Walking Or Upper arm movements Or sit/stand	07:30-09:30		09:30-11:30		11:30-13:30		13:30-15:30		15:30-17:30		17:30-19:30		**Comments**
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	
	X		X			X		X	X			X	09:30-11:30 resident declined; 11:30-15:30 resident off the ward; 17:30-19:30 resident declined.

3. You are required to write details of between meal snacks offered to the resident. For each period, you may write for example 2 X short bread to indicate that two short breads were offered. In the comment section of the research activities chart, please make a short remark to indicate whether the resident ate all, half, or 1/3 of the snack; or whether the resident refused the snack.

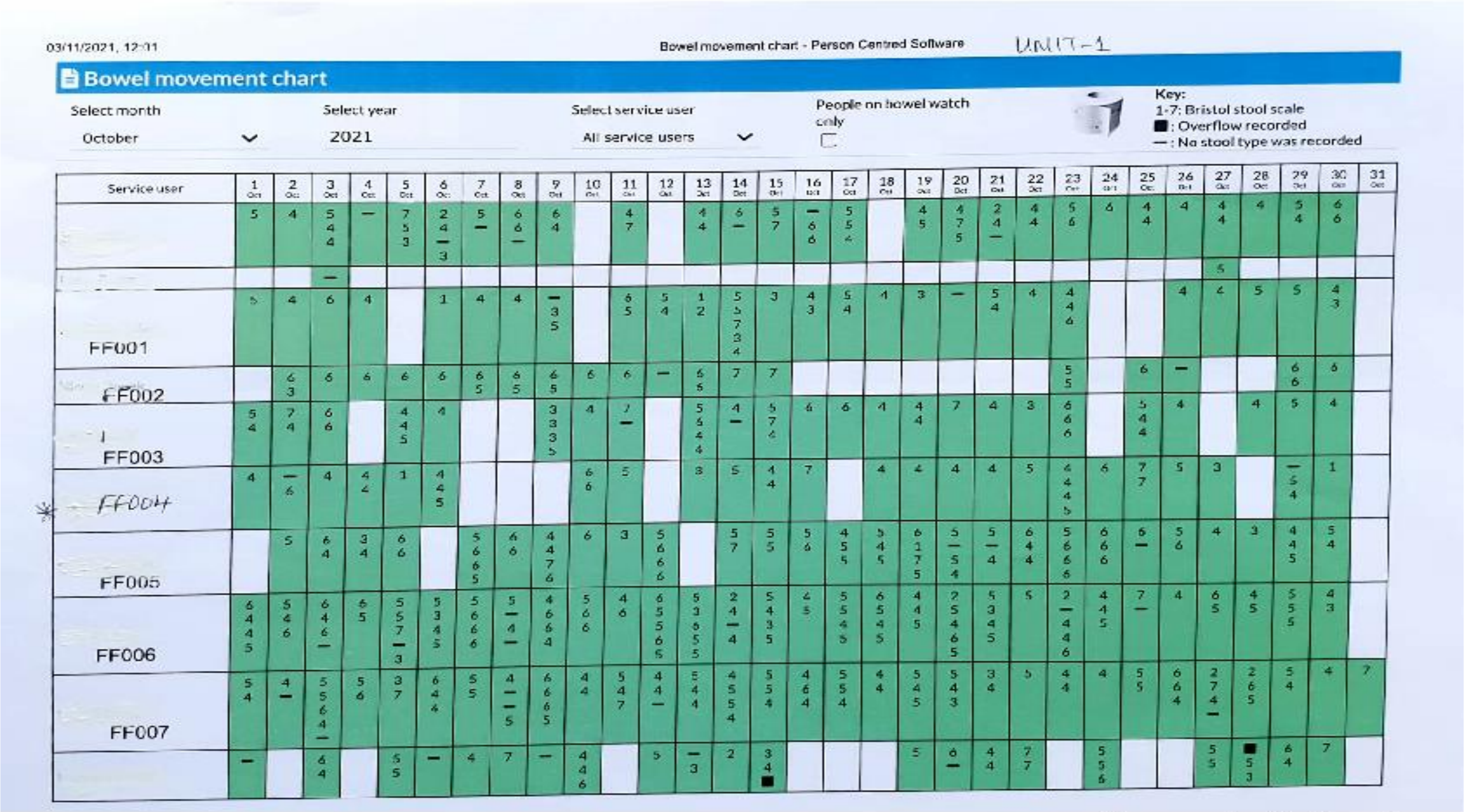
Between meals Snacks	First snack detail	Second snack detail	Third snack detail	Comments
	2 x digestive biscuit	1 x shortbread	1 x slice of bread (toast)	

4. For the fluid part, you are required to state the actual volume the resident has drunk. Do not put tick in any of the boxes here. Please see example below.

Fluid intake	Water	Milk	Tea or coffee	Others	Comments
07:30 – 09:30	100ml 150ml		150ml tea		
09:30 – 11:30				200ml squash 50ml medication	
11:30 – 13:30	200ml	100ml			
13:30 – 15:30					Resident went off the ward

Appendix 28: Bowel diaries from baseline to the 8th week of ImFaCON intervention

Unit-1 Bowel diaries for October 21, December 21, and January 22



03/11/2021, 12:11 Bowel movement chart - Person Centred Software UNIT-1

Bowel movement chart

Select month: October

Select year: 2021

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■ : Overflow recorded
— : No stool type was recorded

Service user	1 Oct	2 Oct	3 Oct	4 Oct	5 Oct	6 Oct	7 Oct	8 Oct	9 Oct	10 Oct	11 Oct	12 Oct	13 Oct	14 Oct	15 Oct	16 Oct	17 Oct	18 Oct	19 Oct	20 Oct	21 Oct	22 Oct	23 Oct	24 Oct	25 Oct	26 Oct	27 Oct	28 Oct	29 Oct	30 Oct	31 Oct
[redacted]	5	4	5 4 4	—	7 5 3	2 4 — 3	5 —	6 6 —	6 4		4 7		4 4	6 —	5 7	— 6 6	5 5 4		4 5	4 7 5	2 4 —	4 4	5 6	6	4 4	4	4 4	4	5 4	6 6	
[redacted]			—																								5				
FF001	5	4	6	4		1	4	4	— 3 5		6 5	5 4	1 2	5 5 7 3 4	3	4 3	5 4	4	3	—	5 4	4	4 4 6			4	4	5	5	4 3	
FF002		6 3	6	6	6	6	6 5	6 5	6 5	6	6	—	6 6	7	7								5 5		6	—			6 6	6	
FF003	5 4	7 4	6 6		4 4 5	4			3 3 3 5	4	7 —		5 5 4 4	4 —	5 7 4	6	6	4	4 4	7	4	3	6 6 6		5 4 4	4		4	5	4	
* FF004	4	— 6	4	4 4	1	4 4 5				6 6	5		3	5	4 4	7		4	4	4	4	5	4 4 4 5	6	7 7	5	3		— 5 4	1	
FF005		5	6 4	3 4	6 6		5 6 6 5	6 6	4 4 7 6	6	3	5 6 6 6		5 7	5 5	5 6	4 5 5	5 4 5	6 1 7 5	5 — 5 4	5 — 4	6 4 4	5 6 6 6	6 6 6	6 —	5 6	4	3	4 4 5	5 4	
FF006	6 4 4 5	5 4 6	6 4 6 —	6 5	5 5 7 — 3	5 3 4 5	5 6 6 6	5 — 4 —	4 6 6 4	5 6 6	4 6	6 5 5 6 5	5 3 6 5 5	2 4 — 4	5 4 3 5	4 5	5 5 4 5	6 5 4 5	4 4 5	2 5 4 6 5	5 3 4 5	5	2 — 4 4 6	4 4 5	7 —	4	6 5	4 5	5 5 5	4 3	
FF007	5 4	4 —	5 5 6 4 —	5 6	3 7	6 4 4	5 5	4 — — 5	6 6 6 5	4 4	5 4 7	4 4 —	5 4 4	4 5 5 4	5 5 4	4 6 4	5 5 4	4 4	5 4 5	5 4 3	3 4	5	4 4	4	5 5	6 6 4	2 7 4 —	2 6 5	5 4	4	7
[redacted]	—		6 4		5 5	—	4	7	—	4 4 6		5	— 3	2	3 4 ■				5	6 —	4 4	7 7		5 5 6			5 5	■ 5 3	6 4	7	

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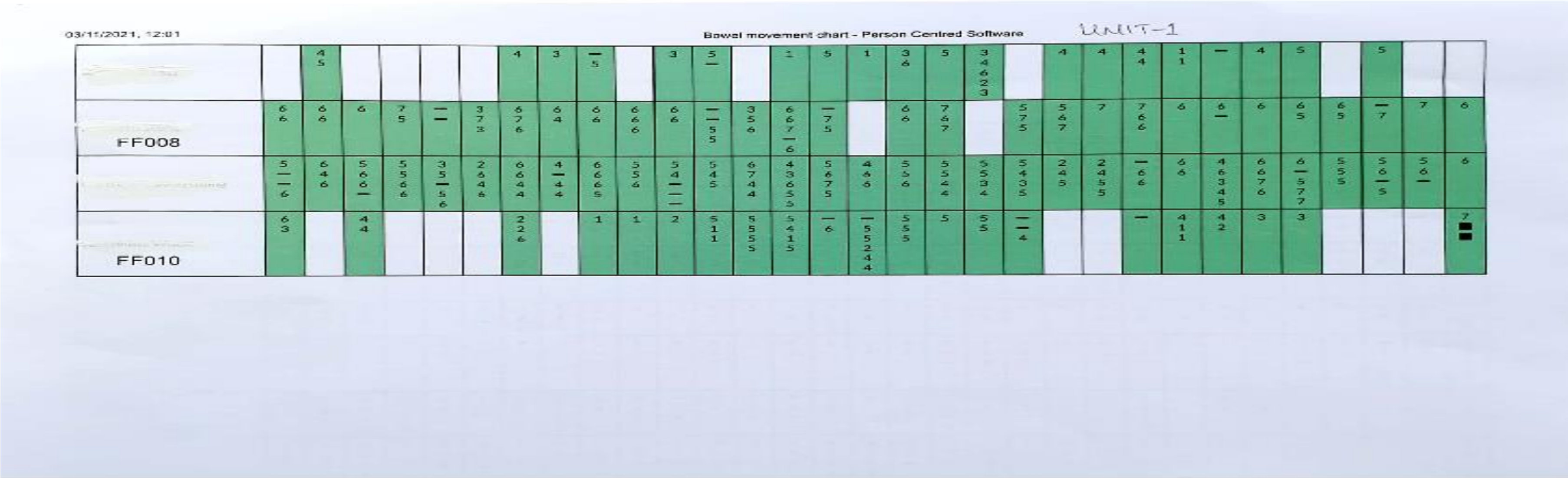
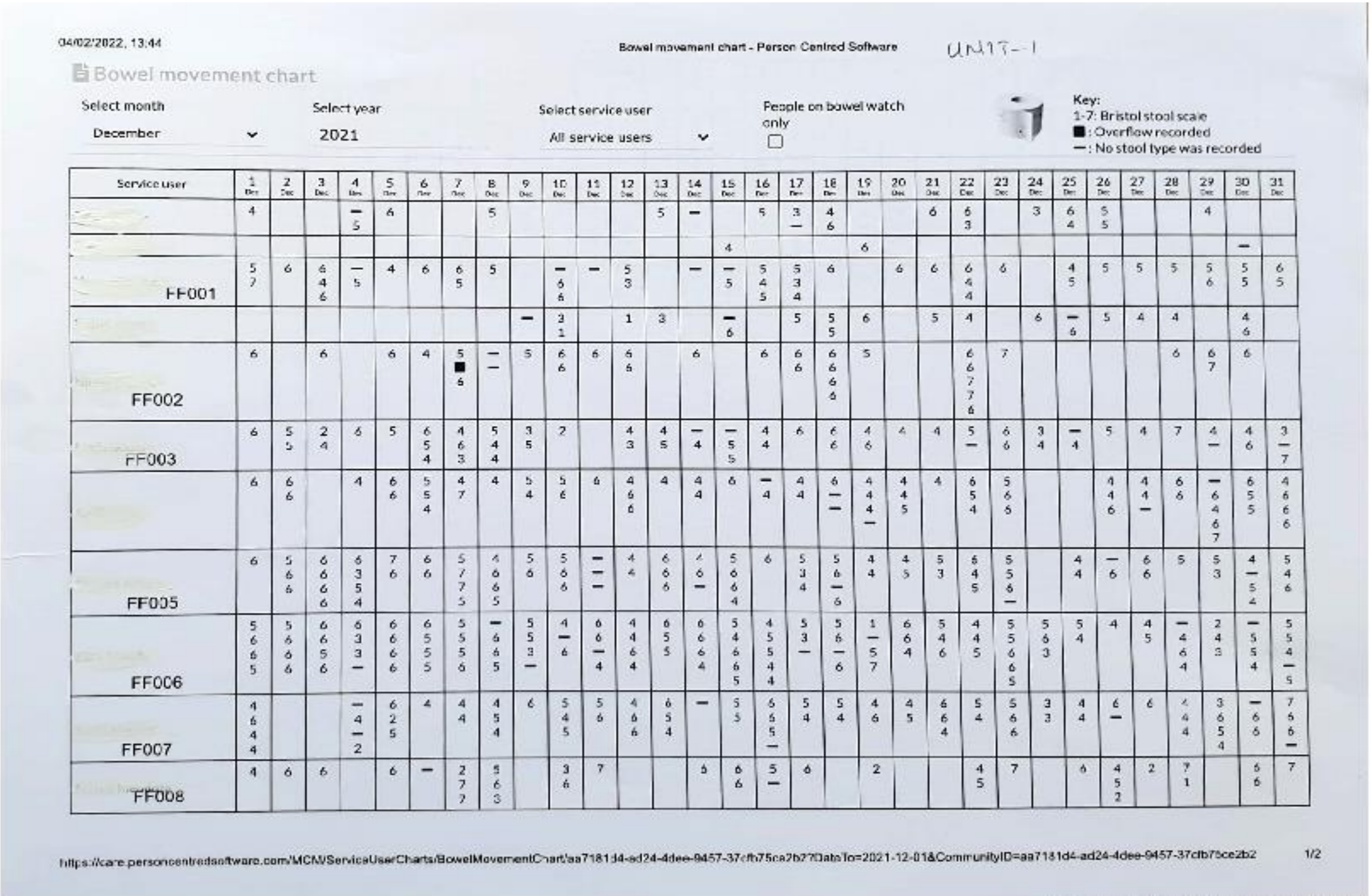


03/11/2021, 12:01

Bowel movement chart - Person Centred Software

UNIT-1

[redacted]		4 5					4	3	— 5		3	5 —		1	5	1	3 6	5	3 4 6 2 3		4	4	4 4	1 1	—	4	5		5		
[redacted] FF008	6 6	6 6	6	7 5	— —	3 7 3	6 7 6	6 4	6 6	6 6 6	6 6	— — 5 5	3 5 6	6 6 7 — 6	— 7 5		6 6	7 6 7		5 7 5	5 6 7	7	7 6 6	6	6 —	6	6 5	6 5	— 7	7	6
[redacted]	5 — — 6	6 4 6	5 6 6 —	5 5 6 6	3 5 — 5 6	2 6 4 6	6 6 4 4	4 — 4 4	6 6 6 5	5 5 6	5 4 — — —	5 4 5	6 7 4 4	4 3 6 5 5	5 6 7 5	4 4 6	5 5 6	5 5 4 4	5 5 3 4	5 4 3 5	2 4 5	2 4 5 5	— 6 6	6 6	4 6 3 4 5	6 6 7 6	6 — 5 7 7	5 5 5	5 6 — 5	5 6 —	6
[redacted] FF010	6 3		4 4				2 2 6		1	1	2	5 1 1	5 5 5 5	5 4 1 5	— 6	— 5 5 2 4 4	5 5 5	5	5 5	— — 4			—	4 1 1	4 2	3	3				7 ■ ■



UN13-1

Bowel movement chart

Select month: December

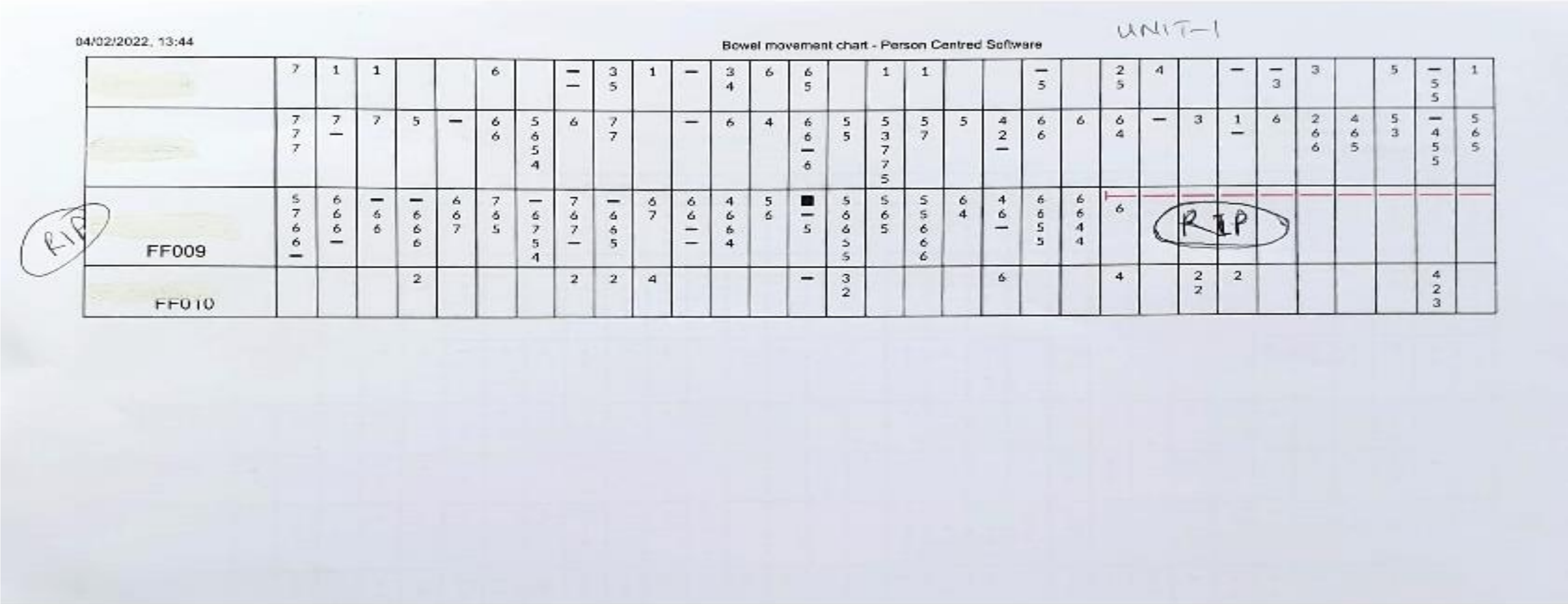
Select year: 2021

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■: Overflow recorded
—: No stool type was recorded

Service user	1 Dec	2 Dec	3 Dec	4 Dec	5 Dec	6 Dec	7 Dec	8 Dec	9 Dec	10 Dec	11 Dec	12 Dec	13 Dec	14 Dec	15 Dec	16 Dec	17 Dec	18 Dec	19 Dec	20 Dec	21 Dec	22 Dec	23 Dec	24 Dec	25 Dec	26 Dec	27 Dec	28 Dec	29 Dec	30 Dec	31 Dec
[redacted]	4			— 5	6			5					5	—		5	3 —	4 6			6	6 3		3	6 4	5 5			4		
[redacted]															4				6											—	
[redacted] FF001	5 7	6	6 4 6	— 5	4	6	6 5	5		— 6 6	—	5 3		—	— 5	5 4 5	5 3 4	6		6	6	6 4 4	6		4 5	5	5	5	5 6	5 5	6 5
[redacted]									—	3 1		1	3		— 6		5	5 5	6		5	4		6	— 6	5	4	4		4 6	
[redacted] FF002	6		6		6	4	5 ■ 6	— —	5	6 6	6	6 6		6		6	6 6	6 6 6 6	5			6 6 7 7 6	7					6	6 7	6	
[redacted] FF003	6	5 5	2 4	6	5	6 5 4	4 6 3	5 4 4	3 5	2		4 3	4 5	— 4	— 5 5	4 4	6	6 6	4 6	4	4	5 —	6 6	3 4	— 4	5	4	7	4 —	4 6	3 — 7
[redacted]	6	6 6		4	6 6	5 5 4	4 7	4	5 4	5 6	6	4 6 6	4	4 4	6	— 4	4 4	6 — —	4 4 4 —	4 4 5	4	6 5 4	5 6 6			4 4 6	4 4 —	6 6	— 6 4 6 7	6 5 5	4 6 6 6
[redacted] FF005	6	5 6 6	6 6 6 6	6 3 5 4	7 6	6 6	5 7 7 5	4 6 6 5	5 6	5 6 6	— — —	4 4	6 6 6	4 6 —	5 6 6 4	6	5 3 4	5 6 — 6	4 4	4 5	5 3	6 4 5	5 5 6 —		4 4	— 6	6 6	5	5 3	4 — 5 4	5 4 6
[redacted] FF006	5 6 6 5	5 6 6 6	6 6 5 6	6 3 3 —	6 6 6 6	6 5 5 5	5 5 5 6	— 6 6 5	5 5 3 —	4 — 6	6 6 — 4	4 4 6 4	6 5 5	6 6 6 4	5 4 6 6 5	4 5 5 4 4	5 3 —	5 6 — 6	1 — 5 7	6 6 4	5 4 6	4 4 5	5 5 6 6 5	5 6 3	5 4	4	4 5	— 4 6 4	2 4 3	— 5 5 4	5 5 4 — 5
[redacted] FF007	4 6 4 4			— 4 — 2	6 2 5	4	4 4	4 5 4	6	5 4 5	5 6	4 6 6	6 5 4	—	5 5	6 6 5 —	5 4	5 4	4 6	4 5	6 6 4	5 4	5 6 6	3 3	4 4	6 —	6	4 4 4	3 6 5 4	— 6 6	7 6 6 —
[redacted] FF008	4	6	6		6	—	2 7 7	5 6 3		3 6	7			6	6 6	5 —	6		2			4 5	7		6	4 5 2	2	7 1		6 6	7



04/02/2022, 13:44

Bowel movement chart - Person Centred Software

UNIT-1

[redacted]	7	1	1			6		— —	3 5	1	—	3 4	6	6 5		1	1			— 5		2 5	4		—	— 3	3		5	— 5 5	1
[redacted]	7 7 7	7 —	7	5	—	6 6	5 6 5 4	6	7 7		—	6	4	6 6 — 6	5 5	5 3 7 7 5	5 7	5	4 2 —	6 6	6	6 4	—	3	1 —	6	2 6 6	4 6 5	5 3	— 4 5 5	5 6 5
RIP [redacted] FF009	5 7 6 6 —	6 6 6 —	— 6 6	— 6 6 6	6 6 7	7 6 5	— 6 7 5 4	7 6 7 —	— 6 6 5	6 7	6 6 — —	4 6 6 4	5 6	■ — 5	5 6 6 5 5	5 6 5	5 5 6 6 6	6 4	4 6 —	6 6 5 5	6 6 4 4	6	RIP								
[redacted] FF010				2				2	2	4				—	3 2				6			4		2 2	2					4 2 3	

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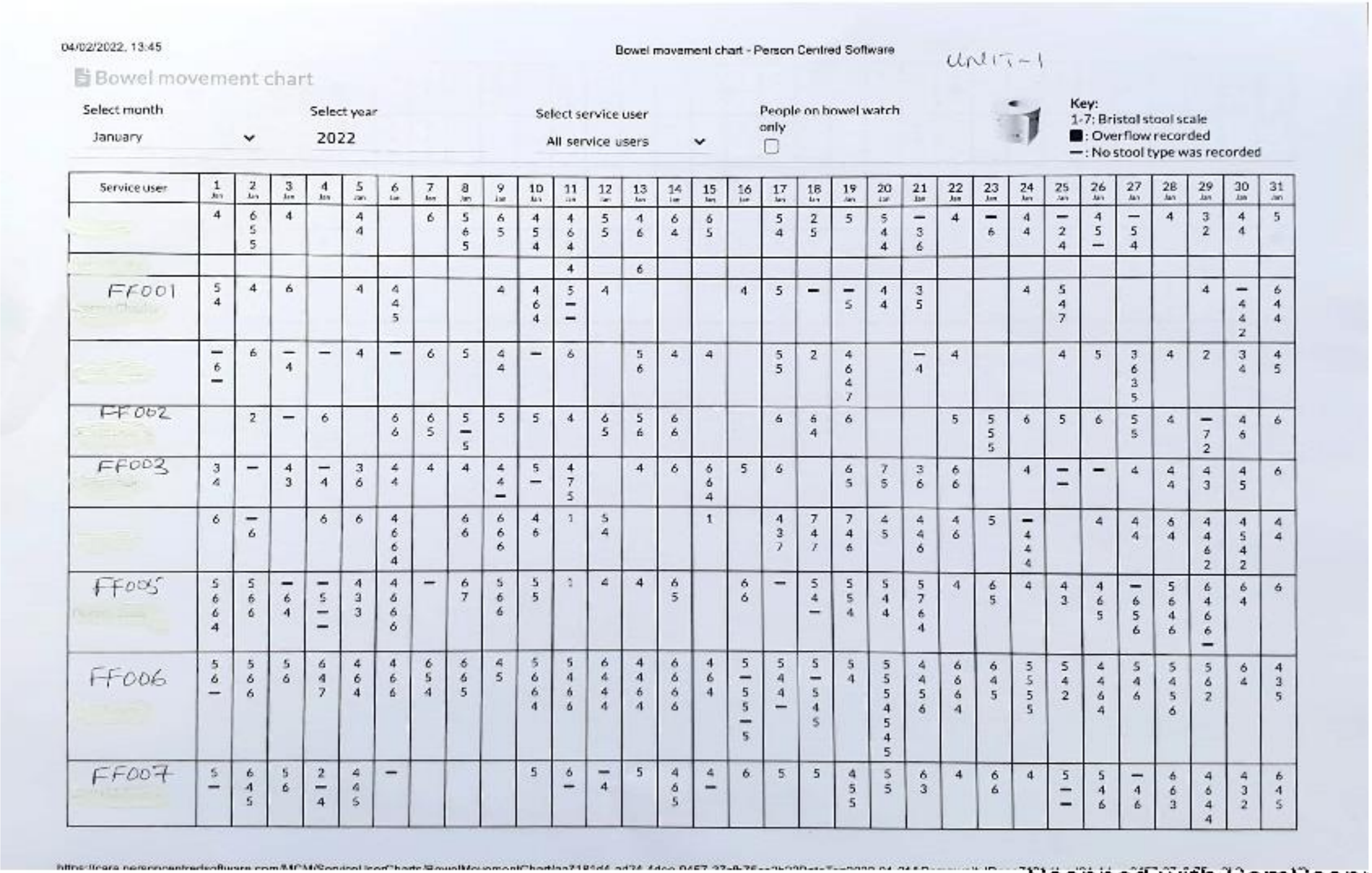


UNIT-1

Bowel movement chart

Select month: January

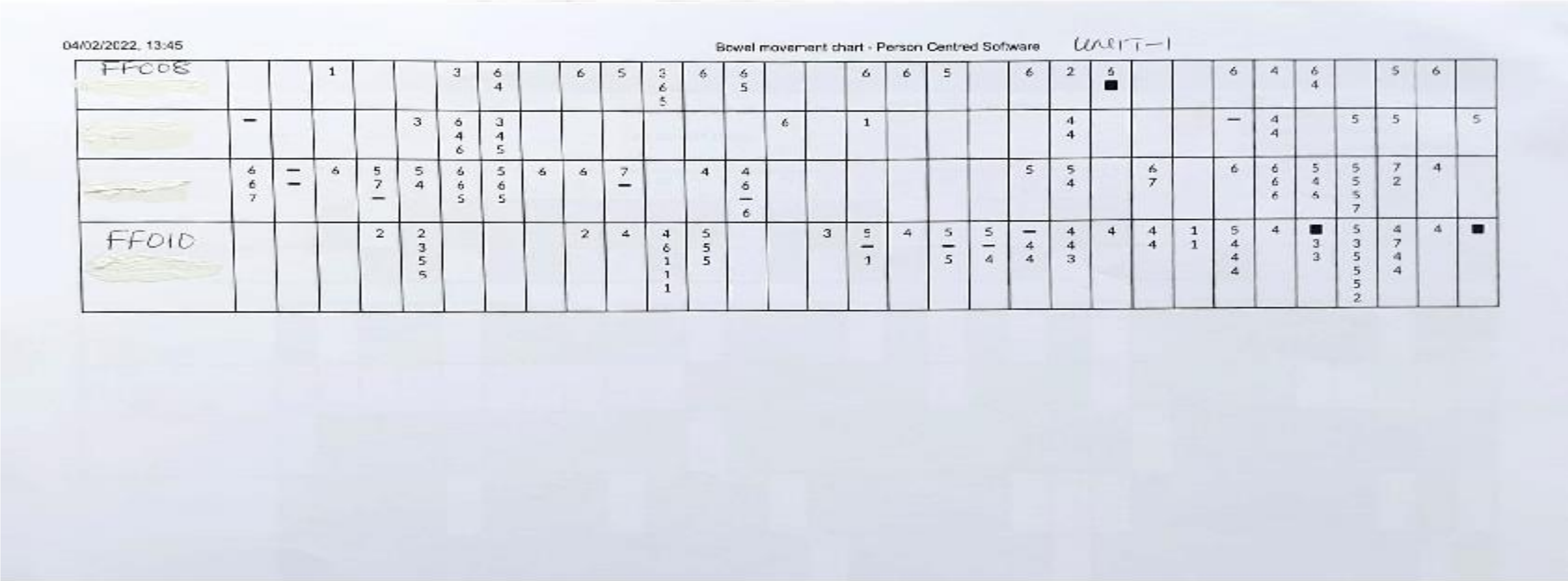
Select year: 2022

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■: Overflow recorded
—: No stool type was recorded

Service user	1 Jan	2 Jan	3 Jan	4 Jan	5 Jan	6 Jan	7 Jan	8 Jan	9 Jan	10 Jan	11 Jan	12 Jan	13 Jan	14 Jan	15 Jan	16 Jan	17 Jan	18 Jan	19 Jan	20 Jan	21 Jan	22 Jan	23 Jan	24 Jan	25 Jan	26 Jan	27 Jan	28 Jan	29 Jan	30 Jan	31 Jan
[redacted]	4	6 5 5	4		4 4		6	5 6 5	6 5	4 5 4	4 6 4	5 5	4 6	6 4	6 5		5 4	2 5	5	5 4 4	— 3 6	4	— 6	4 4	— 2 4	4 5 —	— 5 4	4	3 2	4 4	5
[redacted]											4		6																		
FF001 [redacted]	5 4	4	6		4	4 4 5			4	4 6 4	5 — —	4				4	5	—	— 5	4 4	3 5			4	5 4 7				4	— 4 4 2	6 4 4
[redacted]	— 6 —	6	— 4	—	4	—	6	5	4 4	—	6		5 6	4	4		5 5	2	4 6 4 7		— 4	4			4	5	3 6 3 5	4	2	3 4	4 5
FF002 [redacted]		2	—	6		6 6	6 5	5 — 5	5	5	4	6 5	5 6	6 6			6	6 4	6			5	5 5 5	6	5	6	5 5	4	— 7 2	4 6	6
FF003 [redacted]	3 4	—	4 3	— 4	3 6	4 4	4	4	4 4 —	5 —	4 7 5		4	6	6 6 4	5	6		6 5	7 5	3 6	6 6		4	— —	—	4	4 4	4 3	4 5	6
[redacted]	6	— 6		6	6	4 6 6 4		6 6	6 6 6	4 6	1	5 4			1		4 3 7	7 4 7	7 4 6	4 5	4 4 6	4 6	5	— 4 4 4		4	4 4	6 4	4 4 6 2	4 5 4 2	4 4
FF005 [redacted]	5 6 6 4	5 6 6	— 6 4	— 5 — —	4 3 3	4 6 6 6	—	6 7	5 6 6	5 5	1	4	4	6 5		6 6	—	5 4 —	5 5 4	5 4 4	5 7 6 4	4	6 5	4	4 3	4 6 5	— 6 5 6	5 6 4 6	6 4 6 6 —	6 4	6
FF006 [redacted]	5 6 —	5 6 6	5 6	6 4 7	4 6 4	4 6 6	6 5 4	6 6 5	4 5	5 6 6 4	5 4 6 6	6 4 4 4	4 4 6 4	6 6 6 6	4 6 4	5 — 5 5 — 5	5 4 4 —	5 — 5 4 5	5 4	5 5 5 4 5 4 5	4 4 5 6	6 6 6 4	6 4 5	5 5 5 5	5 4 2	4 4 6 4	5 4 6	5 4 5 6	5 6 2	6 4	4 3 5
FF007 [redacted]	5 —	6 4 5	5 6	2 — 4	4 4 5	—				5	6 —	— 4	5	4 6 5	4 —	6	5	5	4 5 5	5 5	6 3	4	6 6	4	5 — —	5 4 6	— 4 6	6 6 3	4 6 4 4	4 3 2	6 4 5

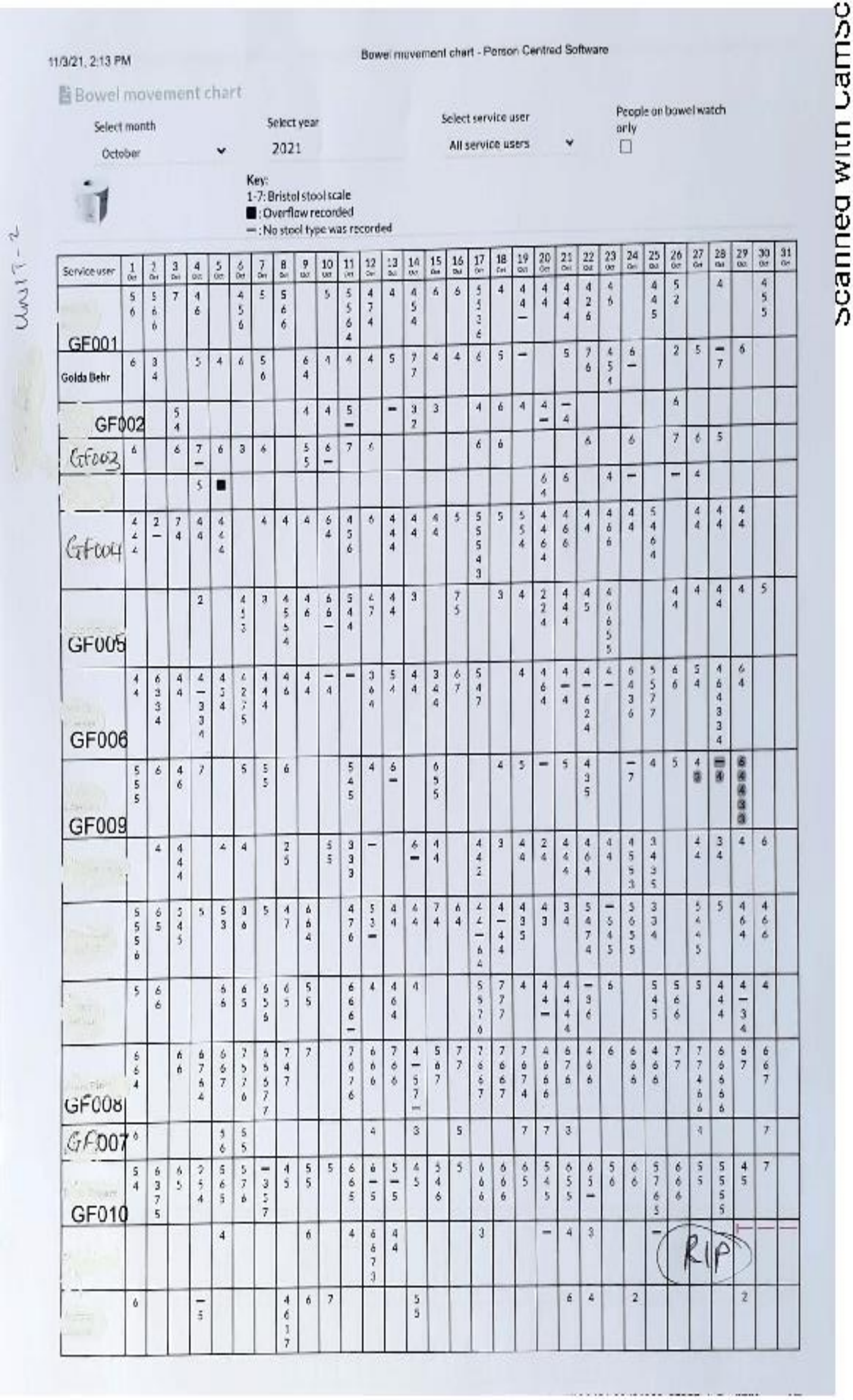


04/02/2022, 13:45

Bowel movement chart - Person Centred Software UNIT-1

FF008 [redacted]			1			3	6 4		6	5	3 6 5	6	6 5			6	6	5		6	2	5 ■			6	4	6 4		5	6	
[redacted]	—				3	6 4 6	3 4 5							6		1					4 4				—	4 4		5	5		5
[redacted]	6 6 7	— —	6	5 7 —	5 4	6 6 5	5 6 5	6	6	7 —		4	4 6 — 6							5	5 4		6 7		6	6 6 6	5 4 6	5 5 5 7	7 2	4	
FF010 [redacted]				2	2 3 5 5				2	4	4 6 1 1 1	5 5 5			3	5 — 1	4	5 — 5	5 — 4	— 4 4	4 4 3	4	4 4	1 1	5 4 4 4	4	■ 3 3	5 3 5 5 5 2	4 7 4 4	4	■

Unit-2 Bowel dairies for October 21, December 21, and January 22



Unit-2

11/3/21, 2:13 PM

Bowel movement chart - Person Centred Software

Bowel movement chart

Select month: October

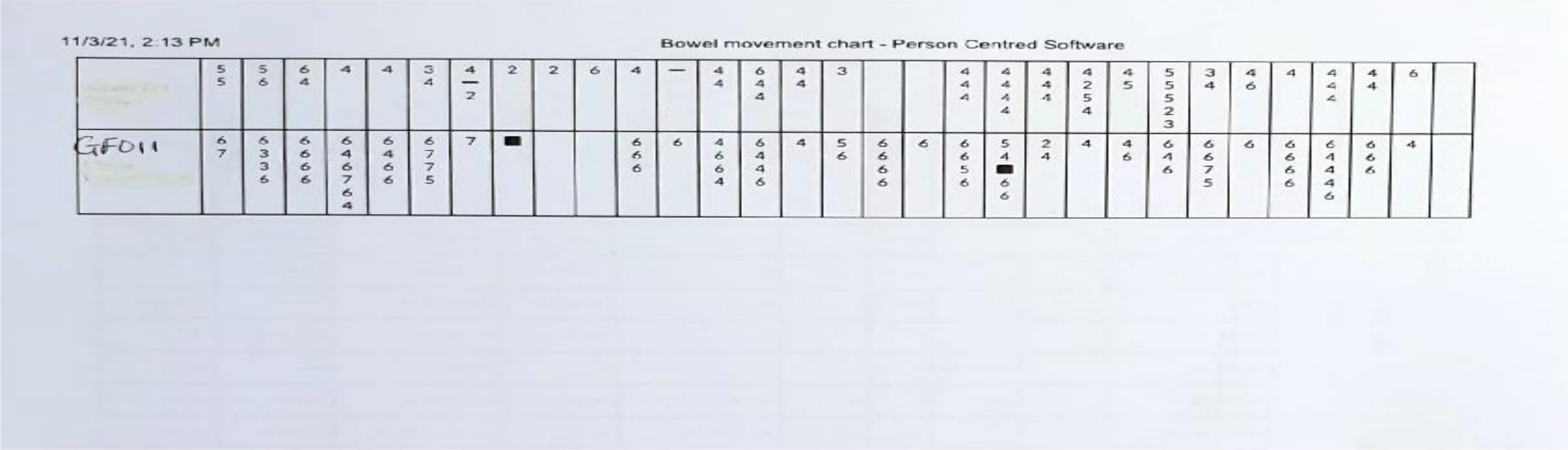
Select year: 2021

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■ : Overflow recorded
— : No stool type was recorded

Service user	1 Oct	2 Oct	3 Oct	4 Oct	5 Oct	6 Oct	7 Oct	8 Oct	9 Oct	10 Oct	11 Oct	12 Oct	13 Oct	14 Oct	15 Oct	16 Oct	17 Oct	18 Oct	19 Oct	20 Oct	21 Oct	22 Oct	23 Oct	24 Oct	25 Oct	26 Oct	27 Oct	28 Oct	29 Oct	30 Oct	31 Oct
GF001	5 6	5 6 6	7	4 6		4 5 6	5	5 6 6		5	5 5 6 4	4 7 4	4	4 5 4	6	6	5 5 3 6	4	4 4 —	4 4	4 4 4	4 2 6	4 6		4 4 5	5 2		4		4 5 5	
Golda Behr	6	3 4		5	4	6	5 6		6 4	4	4	4	5	7 7	4	4	6	5	—		5	7 6	4 5 4	6 —		2	5	— 7	6		
GF002			5 4						4	4	5 —		—	3 2	3		4	6	4	4 —	— 4					6					
Gf003	6		6	7 —	6	3	6		5 5	6 —	7	6					6	6				6		6		7	6	5			
				5	■															6 4	6		4	—		—	4				
Gf004	4 4 4	2 —	7 4	4 4	4 4 4		4	4	4	6 4	4 5 6	6	4 4 4	4 4	4 4	5	5 5 5 4 3	5	5 5 4	4 4 6 4	4 6 6	4 4	4 6 6	4 4	5 4 6 4		4 4	4 4	4 4		
GF005				2		4 5 3	3	4 5 5 4	4 6	6 6 —	5 4 4	6 7	4 4	3		7 5		3	4	2 2 4	4 4 4	4 5	4 6 6 5 5			4 4	4	4 4	4	5	
GF006	4 4	6 3 3 4	4 4	4 — 3 3 4	4 3 4	6 2 7 5	4 4 4	4 6	4 4	— 4	—	3 6 4	5 4	4 4	3 4 4	6 7	5 4 7		4	4 6 4	4 — 4	4 — 6 2 4	4 —	6 4 3 6	5 5 7 7	6 6	5 4	4 6 4 3 3 4	6 4		
GF009	5 5 5	6	4 6	7		5	5 5	6			5 4 5	4	6 —		6 5 5			4	5	—	5	4 3 5		— 7	4	5	4 3	— 4	6 6 4 3 3		
		4	4 4 4		4	4		2 5		5 5	3 3 3	—		6 —	4 4		4 4 2	3	4 4	2 4	4 4 4	4 6 4	4 4	4 5 5 3	3 4 3 5		4 4	3 4	4	6	
	5 5 5 6	6 5	5 4 5	5	5 3	3 6	5	4 7	6 6 4		4 7 6	5 3 —	4 4	6 4	7 4	6 4	4 4 — 6 4	4 — 4 4	4 3 5	4 3	3 4	5 4 7 4	— 5 4 5	5 6 5 5	3 3 4		5 4 4 5	5	4 6 4	4 6 6	
	5	6 6			6 6	6 5	6 5 6	6 5	5 5		6 6 6 —	4	4 6 4	4			5 5 7 6	7 7 7	4	4 4 —	4 4 4 4	— 3 6	6		5 4 5	5 6 6	5	4 4 4	4 — 3 4	4	
GF008	6 6 4		6 6	6 7 6 4	6 6 7	7 5 7 6	6 5 5 7 7	7 4 7	7		7 6 7 6	6 6 6	7 6 6	4 — 5 7 —	5 6 7	7 7	7 6 6 7	7 6 6 7	7 6 7 4	4 6 6 6	6 7 6	4 6 6	6	6 6 6	4 6 6	7 7	7 7 4 6 6	6 6 6 6 6	6 7	6 6 7	
GF007	6				5 6	5 5						4		3		5			7	7	3						4			7	
GF010	5 4	6 3 7 5	6 5	7 5 4	5 6 5	5 7 6	— 3 5 7	4 5	5 5	5	6 6 5	6 — 5	5 — 5	4 5	5 4 6	5	6 6 6	6 6 6	6 5	5 4 5	6 5 5	6 5 —	5 6	6 6	5 7 6 5	6 6 6	5 5	5 5 5 5	4 5	7	
					4				6		4	6 6 7 3	4 4				3			—	4	3			—		RIP				
	6			— 5				4 6 3 7	6	7				5 5							6	4		2					2		



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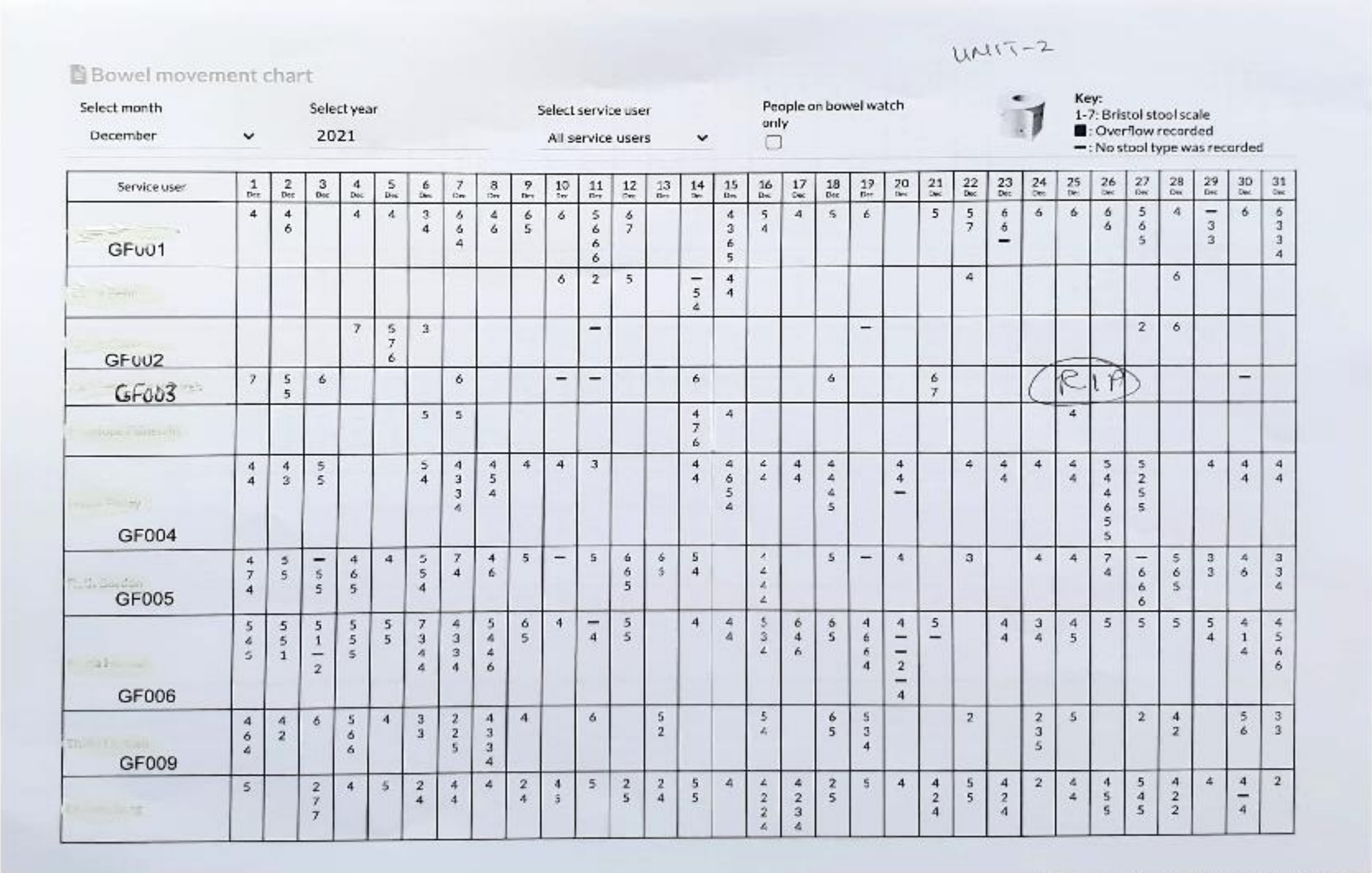
Bowel movement chart - Person Centred Software

[illegible]	5 5	5 6	6 4	4	4	3 4	4 — 2	2	2	6	4	—	4 4	6 4 4	4 4	3			4 4 4	4 4 4 4	4 4 4	4 2 5 4	4 5	5 5 5 2 3	3 4	4 6	4	4 4 4	4 4	6	
GF011	6 7	6 3 3 6	6 6 6 6	6 4 6 7 6 4	6 4 6 6	6 7 7 5	7	■			6 6 6	6	4 6 6 4	6 4 4 6	4	5 6	6 6 6 6	6	6 6 5 6	5 4 ■ 6 6	2 4	4	4 6	6 4 6	6 6 7 5	6	6 6 6 6	6 4 4 4 6	6 6 6	4	



UNIT-2

Bowel movement chart

Select month: December

Select year: 2021

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■: Overflow recorded
—: No stool type was recorded

Service user	1 Dec	2 Dec	3 Dec	4 Dec	5 Dec	6 Dec	7 Dec	8 Dec	9 Dec	10 Dec	11 Dec	12 Dec	13 Dec	14 Dec	15 Dec	16 Dec	17 Dec	18 Dec	19 Dec	20 Dec	21 Dec	22 Dec	23 Dec	24 Dec	25 Dec	26 Dec	27 Dec	28 Dec	29 Dec	30 Dec	31 Dec
[redacted] GF001	4	4 6		4	4	3 4	6 6 4	4 6	6 5	6	5 6 6 6	6 7			4 3 6 5	5 4	4	5	6		5	5 7	6 6 —	6	6	6 6	5 6 5	4	— 3 3	6	6 3 3 4
[redacted]										6	2	5		— 5 4	4 4							4						6			
[redacted] GF002				7	5 7 6	3					—								—								2	6			
[redacted] GF003	7	5 5	6				6			—	—			6				6			6 7				RIP					—	
[redacted]						5	5							4 7 6	4										4						
[redacted] GF004	4 4	4 3	5 5			5 4	4 3 3 4	4 5 4	4	4	3			4 4	4 6 5 4	4 4	4 4	4 4 4 5		4 4 —		4	4 4	4	4 4	5 4 4 6 5 5	5 2 5 5		4	4 4	4 4
[redacted] GF005	4 7 4	5 5	— 5 5	4 6 5	4	5 5 4	7 4	4 6	5	—	5	6 6 5	6 5	5 4		4 4 4 4		5	—	4		3		4	4	7 4	— 6 6 6	5 6 5	3 3	4 6	3 3 4
[redacted] GF006	5 4 5	5 5 1	5 1 — 2	5 5 5	5 5	7 3 4 4	4 3 3 4	5 4 4 6	6 5	4	— 4	5 5		4	4 4	5 3 4	6 4 6	6 5	4 6 6 4	4 — — 2 — 4	5 —		4 4	3 4	4 5	5	5	5	5 4	4 1 4	4 5 6 6
[redacted] GF009	4 6 4	4 2	6	5 6 6	4	3 3	2 2 5	4 3 3 4	4		6		5 2			5 4		6 5	5 3 4			2		2 3 5	5		2	4 2		5 6	3 3
[redacted]	5		2 7 7	4	5	2 4	4 4	4	2 4	4 5	5	2 5	2 4	5 5	4	4 2 2 4	4 2 3 4	2 5	5	4	4 2 4	5 5	4 2 4	2	4 4	4 5 5	5 4 5	4 2 2	4	4 — 4	2

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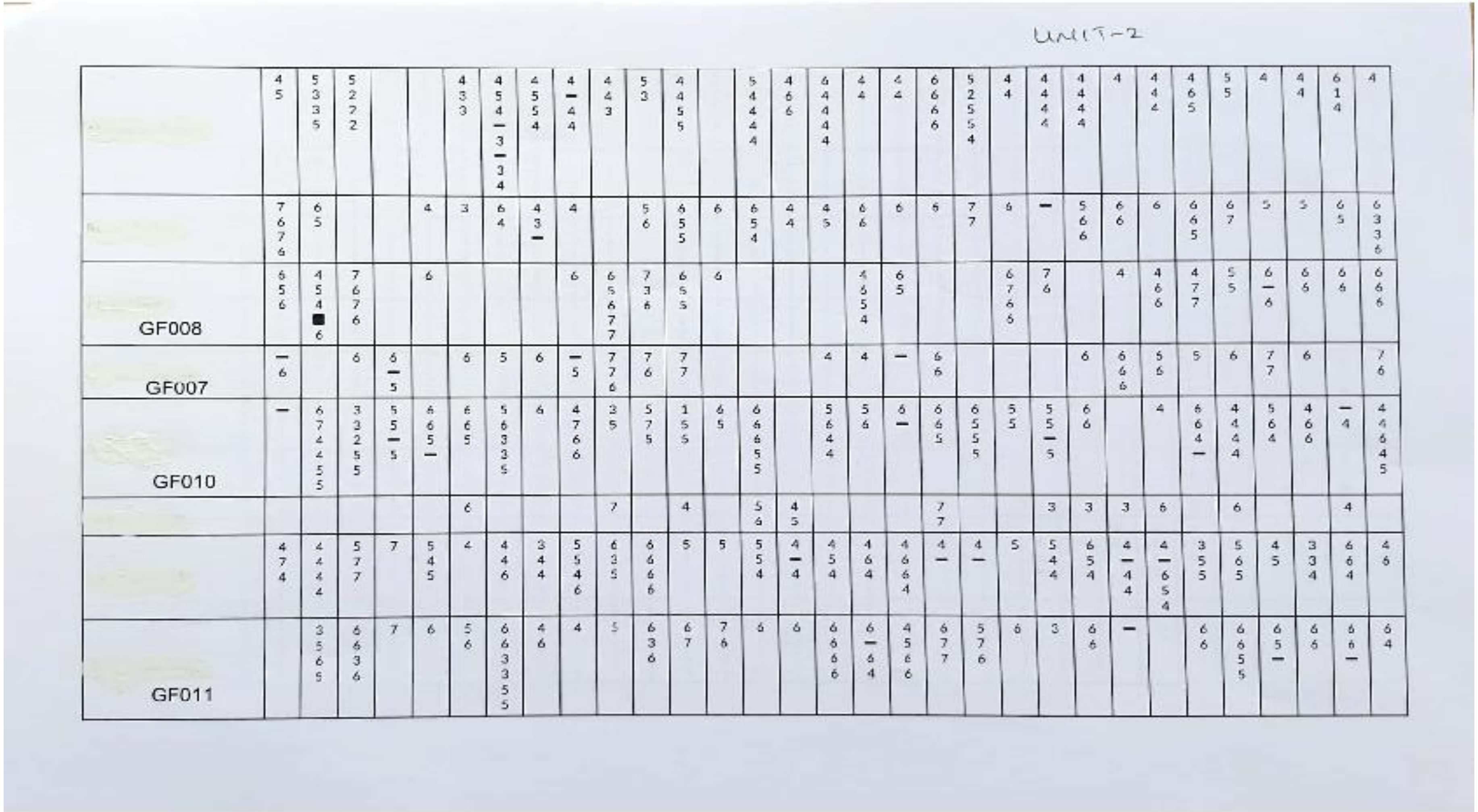
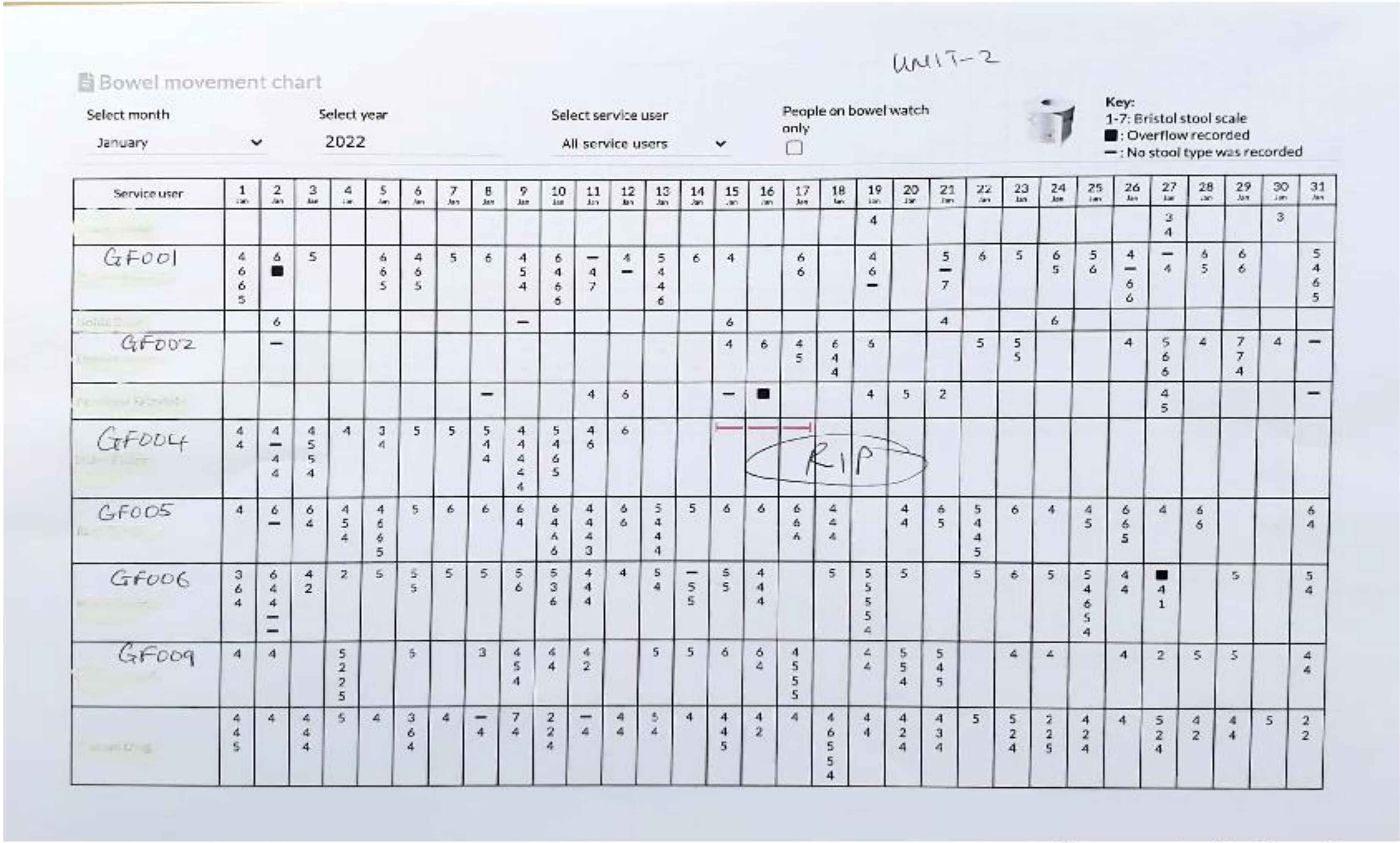


UNIT-2

	4 5	5 3 3 5	5 2 7 2			4 3 3	4 5 4 — 3 — 3 4	4 5 5 4	4 — 4 4	4 4 3	5 3	4 4 5 5		5 4 4 4 4	4 6 6	6 4 4 4 4	4 4	4 4	6 6 6 6	5 2 5 5 4	4 4	4 4 4 4	4 4 4 4	4	4 4 4	4 6 5	5 5	4	4 4	6 1 4	4
	7 6 7 6	6 5			4	3	6 4	4 3 —	4		5 6	6 5 5	6	6 5 4	4 4	4 5	6 6	6	6	7 7	6	—	5 6 6	6 6	6	6 6 5	6 7	5	5	6 5	6 3 3 6
GF008	6 5 6	4 5 4 ■ 6	7 6 7 6		6				6	6 5 6 7 7	7 3 6	6 5 5	6				4 6 5 4	6 5			6 7 6 6	7 6		4	4 6 6	4 7 7	5 5	6 — 6	6 6	6 6	6 6 6
GF007	— 6		6	6 — 5		6	5	6	— 5	7 7 6	7 6	7 7				4	4	—	6 6				6	6 6 6	5 6	5	6	7 7	6		7 6
GF010	—	6 7 4 4 5 5	3 3 2 5 5	5 5 — 5	6 6 5 —	6 6 5	5 6 3 3 5	6	4 7 6 6	3 5	5 7 5	1 5 5	6 5	6 6 6 5 5		5 6 4 4	5 6	6 —	6 6 5	6 5 5 5	5 5	5 5 — 5	6 6		4	6 6 4 —	4 4 4 4	5 6 4	4 6 6	— 4	4 4 6 4 5
						6				7		4		5 6	4 5				7 7			3	3	3	6		6			4	
	4 7 4	4 4 4 4	5 7 7	7	5 4 5	4	4 4 6	3 4 4	5 5 4 6	6 3 5	6 6 6 6	5	5	5 5 4	4 — 4	4 5 4	4 6 4	4 6 6 4	4 —	4 —	5	5 4 4	6 5 4	4 — 4 4	4 — 6 5 4	3 5 5	5 6 5	4 5	3 3 4	6 6 4	4 6
GF011		3 5 6 5	6 6 3 6	7	6	5 6	6 6 3 3 5 5	4 6	4	5	6 3 6	6 7	7 6	6	6	6 6 6 6	6 — 6 4	4 5 6 6	6 7 7	5 7 6	6	3	6 6	—		6 6	6 6 5 5	6 5 —	6 6	6 6 —	6 4

UNIT-2



Bowel movement chart

Select month: January

Select year: 2022

Select service user: All service users

People on bowel watch only ☐

Key:
1-7: Bristol stool scale
■ : Overflow recorded
— : No stool type was recorded

Service user	1 Jan	2 Jan	3 Jan	4 Jan	5 Jan	6 Jan	7 Jan	8 Jan	9 Jan	10 Jan	11 Jan	12 Jan	13 Jan	14 Jan	15 Jan	16 Jan	17 Jan	18 Jan	19 Jan	20 Jan	21 Jan	22 Jan	23 Jan	24 Jan	25 Jan	26 Jan	27 Jan	28 Jan	29 Jan	30 Jan	31 Jan
[redacted]																			4								3 4			3	
GF001 [redacted]	4 6 6 5	6 ■	5		6 6 5	4 6 5	5	6	4 5 4	6 4 6 6	— 4 7	4 —	5 4 4 6	6	4		6 6		4 6 —		5 — 7	6	5	6 5	5 6	4 — 6 6	— 4	6 5	6 6		5 4 6 5
[redacted]		6							—						6						4			6							
GF002 [redacted]		—													4	6	4 5	6 4 4	6			5	5 5			4	5 6 6	4	7 7 4	4	—
[redacted]								—			4	6			—	■			4	5	2						4 5				—
GF004 [redacted]	4 4	4 — 4 4	4 5 5 4	4	3 4	5	5	5 4 4	4 4 4 4 4	5 4 6 5	4 6	6						RIP													
GF005 [redacted]	4	6 —	6 4	4 5 4	4 6 6 5	5	6	6	6 4	6 4 6 6	4 4 4 3	6 6	5 4 4 4	5	6	6	6 6 6	4 4 4		4 4	6 5	5 4 4 5	6	4	4 5	6 6 5	4	6 6			6 4
GF006 [redacted]	3 6 4	6 4 4 — —	4 2	2	5	5 5	5	5	5 6	5 3 6	4 4 4	4	5 4	— 5 5	5 5	4 4 4		5	5 5 5 5 4	5		5	6	5	5 4 6 5 4	4 4	■ 4 1		5		5 4
GF009 [redacted]	4	4		5 2 2 5		5		3	4 5 4	4 4	4 2		5	5	6	6 4	4 5 5 5		4 4	5 5 4	5 4 5		4	4		4	2	5	5		4 4
[redacted]	4 4 5	4	4 4 4	5	4	3 6 4	4	— 4	7 4	2 2 4	— 4	4 4	5 4	4	4 4 5	4 2	4	4 6 5 5 4	4 4	4 2 4	4 3 4	5	5 2 4	2 2 5	4 2 4	4	5 2 4	4 2	4 4	5	2 2

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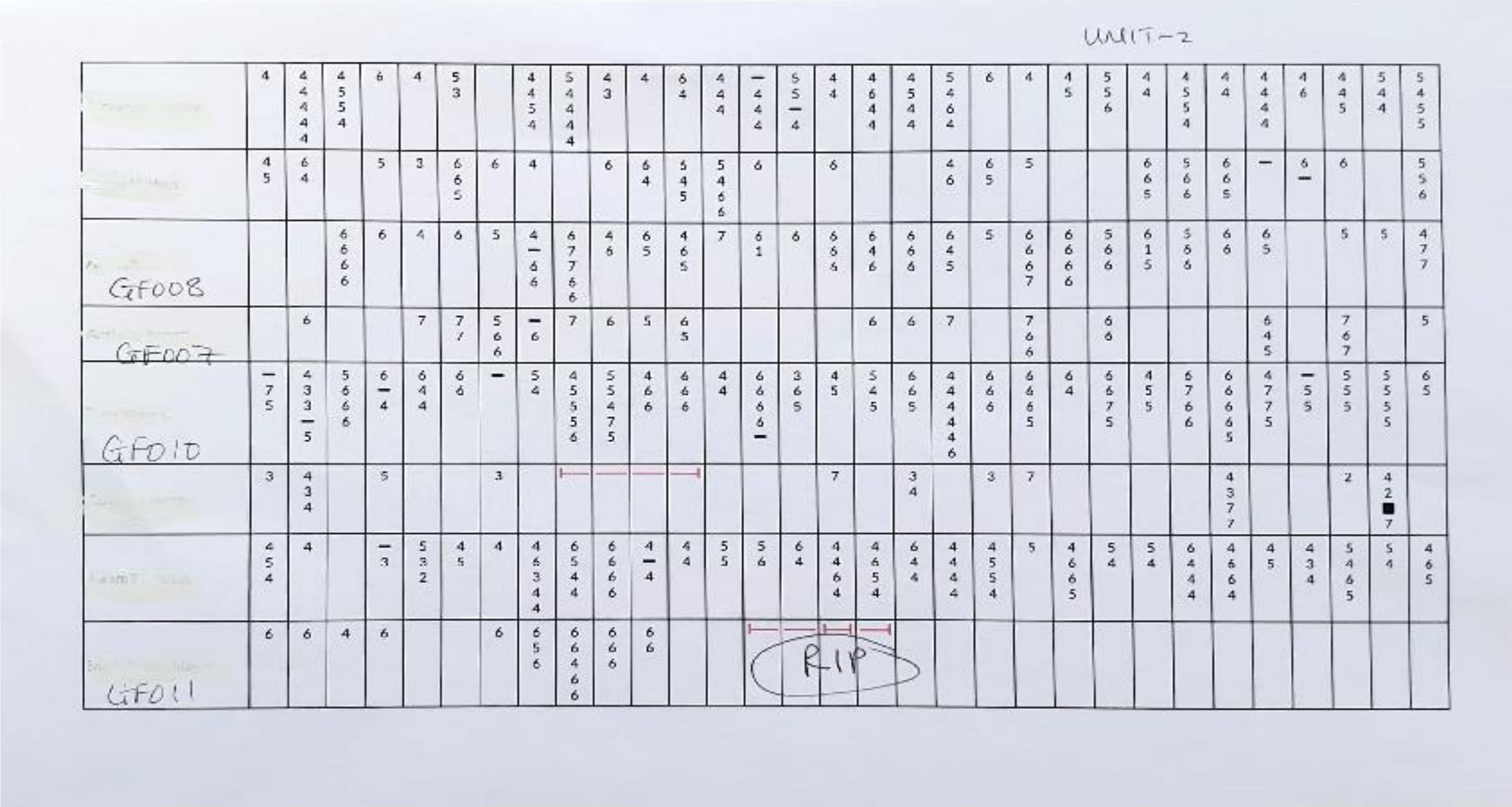

UNIT-2

	4	4 4 4 4 4	4 5 5 4	6	4	5 3		4 4 5 4	5 4 4 4 4	4 3	4	6 4	4 4 4	— 4 4 4	5 5 — 4	4 4	4 6 4 4	4 5 4 4	5 4 6 4	6	4	4 5	5 5 6	4 4	4 5 5 4	4 4	4 4 4 4	4 6	4 4 5	5 4 4	5 4 5 5
	4 5	6 4		5	3	6 6 5	6	4		6	6 4	5 4 5	5 4 6 6	6		6			4 6	6 5	5			6 6 5	5 6 6	6 6 5	—	6 —	6		5 5 6
GF008			6 6 6 6	6	4	6	5	4 — 6 6	6 7 7 6 6	4 6	6 5	4 6 5	7	6 1	6	6 6 6	6 4 6	6 6 6	6 4 5	5	6 6 6 7	6 6 6 6	5 6 6	6 1 5	5 6 6	6 6	6 5		5	5	4 7 7
GF007		6			7	7 7	5 6 6	— 6	7	6	5	6 5					6	6	7		7 6 6		6 6				6 4 5		7 6 7		5
GF010	— 7 5	4 3 3 — 5	5 6 6 6	6 — 4	6 4 4	6 6	—	5 4	4 5 5 5 6	5 5 4 7 5	4 6 6	6 6 6	4 4	6 6 6 6 —	3 6 5	4 5	5 4 5	6 6 5	4 4 4 4 4 6	6 6 6	6 6 6 5	6 4	6 6 7 5	4 5 5	6 7 6 6	6 6 6 6 5	4 7 7 5	— 5 5	5 5 5	5 5 5 5	6 5
	3	4 3 4		5			3									7		3 4		3	7					4 3 7 7			2	4 2 ■ 7	
	4 5 4	4		— 3	5 3 2	4 5	4	4 6 3 4 4	6 5 4 4	6 6 6 6	4 — 4	4 4	5 5	5 6	6 4	4 4 6 4	4 6 5 4	6 4 4	4 4 4 4	4 5 5 4	5	4 6 6 5	5 4	5 4	6 4 4 4	4 6 6 4	4 5	4 3 4	5 4 6 5	5 4	4 6 5
GF011	6	6	4	6			6	6 5 6	6 6 4 6 6	6 6 6	6 6			RIP																	

Appendix 29: The TIDieR (Template for Intervention Description and Replication) Checklist:

Information to include when describing an intervention and the location of the information

Item number	Item	Where located **	
		Primary paper (Page or appendix number)	Other † (details)
	BRIEF NAME		
1.	Provide the name or a phrase that describes the intervention.	____________	______________
	WHY		
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	____________	_____________
	WHAT		
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g., online appendix, URL).	____________	_____________
4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	____________	_____________
	WHO PROVIDED		
5.	For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.	____________	_____________
	HOW		
6.	Describe the modes of delivery (e.g., face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	____________	_____________
	WHERE		

7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	______________	______________
	WHEN and HOW MUCH		
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	______________	______________
	TAILORING		
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	______________	______________
	MODIFICATIONS		
10.ǂ	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	______________	______________
	HOW WELL		
11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	______________	______________
12.	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	______________	______________

Appendix 30: Data collection at baseline, 4 weeks from the start, and four weeks to the end of ImFaCON intervention

Baseline (four weeks prior to the intervention)

Study ID	Age	Sex	Total episodes in one month	Total Type 4 & 5 in one month	Total Types 1-3 in one month	Total Types 6 & 7 in one month	Total overflow in one month
FF001	97	F	38	25 (66%)	9 (24%)	4 (10%)	0
FF002	77	F	24	5 (21%)	1 (4%)	18 (75%)	0
FF003	88	F	42	26 (62%)	4 (9%)	12 (29%)	0
FF004							
FF005	99	F	60	33 (55%)	4 (7%)	23 (38%)	0
FF006	91	F	85	58 (68%)	7 (8%)	20 (24%)	0
FF007	89	F	71	56 (79%)	4 (6%)	11 (15%)	0
FF008	90	M	56	11 (20%)	7 (12%)	38 (68%)	0
FF009	94	F	RIP	RIP	RIP	RIP	RIP
FF010	86	F	44	23 (52%)	15 (34%)	4 (9%)	2 (5%)
GF001	91	F	55	37 (67%)	3 (6%)	15 (27%)	0
GF002	87	M	14	9 (64%)	3 (21%)	2 (15%)	0
GF003	67	F	RIP	RIP	RIP	RIP	RIP
GF004	89	F	RIP	RIP	RIP	RIP	RIP
GF005	96	F	45	31 (68%)	7 (16%)	7 (16%)	0
GF006	92	F	68	42 (62%)	10 (14%)	16 (24%)	0
GF007	94	M	12	6 (50%)	2 (17%)	4 (33%)	0
GF008	102	F	87	10 (11%)	0	77 (89%)	0
GF009	84	F	36	24 (67%)	4 (21%)	8 (22%)	0
GF010	96	F	73	41 (56%)	3 (4%)	29 (40%)	0
GF011	95	F	RIP	RIP	RIP	RIP	RIP

Note: Four of the residents died during the study period (the four residents are highlighted in red coulor, with 'RIP' meaning 'Rest in peace').

Four weeks from the start of the intervention (Week-1 to Week-4)

Study ID	Age	Sex	Total episodes in one month	Total Type 4 & 5 in one month	Total Types 1-3 in one month	Total Types 6 & 7 in one month	Total overflow in one month
FF001	97	F	41	25 (61%)	2 (2%)	15 (37%)	0
FF002	77	F	32	4 (13%)	0	27 (84%)	1 (3%)
FF003	88	F	49	29 (59%)	7 (14%)	13 (27%)	0
FF004							
FF005	99	F	73	35 (48%)	4 (5%)	34 (47%)	0
FF006	91	F	101	56 (55%)	8 (8%)	37 (37%)	0
FF007	89	F	61	35 (57%)	4 (7%)	22 (36%)	0
FF008	90	M	32	7 (22%)	7 (22%)	18 (56%)	0
FF009	94	F	Deceased	Deceased	Deceased	Deceased	Deceased
FF010	86	F	14	2 (29%)	10 (71%)	0	0
GF001	91	F	49	20 (41%)	6 (12%)	23 (47%)	0
GF002	87	M	7	1 (14%)	2 (29%)	4 (57%)	0
GF003	67	F	Deceased	Deceased	Deceased	Deceased	Deceased
GF004	89	F	Deceased	Deceased	Deceased	Deceased	Deceased
GF005	96	F	51	33 (65%)	5 (10%)	13 (25%)	0
GF006	92	F	68	49 (72%)	10 (15%)	9 (13%)	0
GF007	94	M	32	6 (19%)	0	26 (81%)	0
GF008	102	F	56	16 (28%)	1 (2%)	38 (68%)	1 (2%)
GF009	84	F	41	19 (46%)	15 (37%)	7 (17%)	0
GF010	96	F	86	49 (57%)	7 (8%)	30 (35%)	0
GF011	95	F	Deceased	Deceased	Deceased	Deceased	Deceased

Four weeks to the end of the intervention (Week-5 to Week-8)

Study ID	Age	Sex	Total episodes in one month	Total Type 4 & 5 in one month	Total Types 1-3 in one month	Total Types 6 & 7 in one month	Total overflow in one month	St Mark's score
FF001	97	F	32	26 (81%)	2 (6%)	4 (13%)	0	9
FF002	77	F	36	18 (50%)	2 (6%)	16 (44%)	0	11
FF003	88	F	41	24 (59%)	5 (12%)	12 (29%)	0	12
FF004								
FF005	99	F	66	34 (52%)	4 (6%)	28 (42%)	0	12
FF006	91	F	104	69 (66%)	3 (3%)	32 (31%)	0	13
FF007	89	F	53	33 (62%)	5 (13%)	13 (25%)	0	11
FF008	90	M	40	17 (43%)	1 (2%)	22 (55%)	0	10
FF009	94	F	Deceased	Deceased	Deceased	Deceased	Deceased	Deceased
FF010	86	F	53	33 (62%)	16 (30%)	2 (4%)	2 (4%)	9
GF001	91	F	55	29 (53%)	0	25 (45%)	1 (2%)	13
GF002	87	M	20	13 (65%)	0	7 (35%)	0	7
GF003	67	F	Deceased	Deceased	Deceased	Deceased	Deceased	Deceased
GF004	89	F	Deceased	Deceased	Deceased	Deceased	Deceased	Deceased
GF005	96	F	59	34 (58%)	1 (1%)	24 (41%)	0	13
GF006	92	F	55	43 (78%)	5 (9%)	6 (11%)	1 (2%)	10
GF007	94	M	28	6 (21%)	0	22 (79%)	0	9
GF008	102	F	66	18 (27%)	2 (3%)	46 (70%)	0	10
GF009	84	F	40	33 (83%)	5 (13%)	2 (4%)	0	8
GF010	96	F	99	51 (52%)	3 (3%)	45 (45%)	0	12
GF011	95	F	Deceased	Deceased	Deceased	Deceased	Deceased	Deceased

Appendix 31: Abbreviated St Mark’s Score

	Never	Rarely	Sometimes	Weekly	Daily
Incontinence for solid stool	0	1	2	3	4
Incontinence for liquid stool	0	1	2	3	4
Incontinence for gas	0	1	2	3	4
Alteration in lifestyle	0	1	2	3	4
				No	yes
Need to wear a pad				0	1
Taking constipation medicine				0	1
Lack of ability to defer defaecation for 15 minutes				0	1

Never = no episodes in the past four weeks; rarely = 1 episode in the past four weeks; sometimes = > 1 episode in the past four weeks but < 1 a week; weekly = 1 or more episodes a week but < 1 a day; daily = 1 or more episodes a day.

FF001	3+2+1+3 = 9
FF002	3+3+2+3 = 11
FF003	4+3+2+3 =12
FF005	4+3+2+3 = 12
FF006	4+4+2+3 = 13
FF007	3+3+2+3 = 11
FF008	3+3+1+3 = 10
FF010	3+2+1+3 = 9
GF001	4+4+2+3 = 13
GF002	1+2+2+2 = 7
GF005	4+4+2+3 = 13
GF006	4+3+1+2 = 10
GF007	2+3+2+2 = 9
GF008	2+4+2+2 = 10
GF009	3+1+1+3 = 8
GF010	4+4+2+2 = 12

Mean	10.875
SD	1.457738

Mean	10.25
SD	2.251983

Appendix 32: Summary analysis of data

Unit-1 Baseline 6 to 8 Weeks

Type 1-3	Type 4&5	Type 6&7
24	66	10
4	21	75
9	62	29
7	55	38
8	68	24
6	79	15
12	20	68
34	52	9

	Type 1-3	Type 4&5	Type 6&7
Minimum	4	20	9
Q1	6.75	44.25	13.75
Median	8.5	58.5	26.5
Q3	15	66.5	45.5
Maximum	34	79	75
Mean	13	52.875	33.5
Range	30	59	66
IQR	8.25	22.25	31.75
IQR * 1.5	12.375	33.375	47.625
Lower limit	-5.625	10.875	-33.875
Upper limit	27.375	99.875	93.125

Type 1-3	Type 4&5	Type 6&7
6	81	13
6	50	44
12	59	29
6	52	42
3	66	31
13	62	25
2	43	55
30	33	4

	Type 1-3	Type 4&5	Type 6&7
Minimum	2	33	4
Q1	5.25	48.25	22
Median	6	55.5	30
Q3	12.25	63	42.5
Maximum	30	81	55
Mean	9.75	55.75	30.375
Range	28	48	51
IQR	7	14.75	20.5
IQR * 1.5	10.5	22.125	30.75
Lower limit	-5.25	26.125	-8.75
Upper limit	22.75	85.125	73.25

Unit-2 Baseline 6 to 8 Weeks

Type 1-3	Type 4&5	Type 6&7
6	67	27
21	64	15
16	68	16
14	62	24
17	50	33
0	11	89
21	67	22
4	56	40

	Type 1-3	Type 4&5	Type 6&7
Minimum	0	11	15
Q1	9	53	19
Median	15	59	28.5
Q3	17	62	40
Maximum	21	67	89
Mean	12.375	55.625	33.25
Range	21	56	74

Type 1-3	Type 4&5	Type 6&7
0	53	45
0	65	35
1	58	41
9	78	11
0	21	79
3	27	70
13	83	4
3	52	45

	Type 1-3	Type 4&5	Type 6&7
Minimum	0	21	4
Q1	0	45.75	29
Median	2	55.5	43
Q3	4.5	68.25	51.25
Maximum	13	83	79
Mean	3.625	54.625	41.25
Range	13	62	75

IQR	8	9	21
IQR * 1.5	12	13.5	31.5
Lower limit	-3	39.5	-12.5
Upper limit	29	75.5	71.5

IQR	4.5	22.5	22.25
IQR * 1.5	6.75	33.75	33.375
Lower limit	-6.75	12	-4.375
Upper limit	11.25	102	84.625

Appendix 33: Mapping interventions to residents’ needs

Unit-1

Residents	Toileting exercises		Physical exercises		Conservative management	
FF001	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF002	Scheduled toileting	Staff don’t know bowel pattern	Sit and stand 8 times daily	Steady transfer by 2 staff	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF003	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident uses wheelchair	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF005	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF006	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF007	Scheduled toileting	Staff don’t know bowel pattern	Mobile 8 times daily	Resident can walk with Zimmer frame	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF008	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target **2000ml** in 24 hours)
FF009	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
FF010	Scheduled toileting	Staff don’t know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)

Unit-2

Residents	Toileting exercise		Physical exercises		Conservative management	
GF001	Scheduled toileting	Staff don't know bowel pattern.	Upper arm movement 8 times daily	Resident is steady transfer by 2 staff	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF002	Scheduled toileting	Staff don't know bowel pattern	Upper arm movement 8 times daily	Resident uses wheelchair and has diabetic foot ulcers	High fibre snacks	Fluid intake (Target **2000**ml in 24 hours)
GF003	Prompted toileting	Can ask for assistance sometimes	Mobilise 8 times daily	Resident can walk with a 4-wheeler	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF004	Scheduled toileting	Staff don't know bowel pattern	Upper arm movement 8 times daily	Resident is wheelchair bound	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF005	Scheduled toileting	Staff don't know bowel pattern. Doesn't communicate	Upper arm movement 8 times daily	Unable to stand-up; hoist transfer	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF006	Scheduled toileting	Staff don't know bowel pattern. Doesn't communicate	Upper arm movement 8 times daily	Hoist transfer; contractures	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF007	Scheduled toileting	Staff don't know bowel pattern.	Upper arm movement 8 times daily	Resident is wheelchair bound; hoist transfer	High fibre snacks	Fluid intake (Target **2000**ml in 24 hours)
GF008	Prompted toileting	Can ask for assistance sometimes	Upper arm movement 8 times daily	Resident is wheelchair bound and cannot move wheelchair independently	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF009	Scheduled toileting	Opens bowel when hoisted	Upper arm movement 8 times daily	Hoist transfer; uses specialised chair	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF010	Prompted toileting	Can ask for assistance sometimes	Mobilise 8 times daily	Resident can walk with Zimmer frame	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)
GF011	Scheduled toileting	Staff don't know bowel pattern	Upper arm movement 8 times daily	Resident is bedbound; uses specialised chair	High fibre snacks	Fluid intake (Target 1600ml in 24 hours)