STUDY PROTOCOL

A realist review of the causes of, and current interventions to address 'missingness' in health care. [version 1; peer review: 2 approved with reservations]

Calum Lindsay [ID]1, David Baruffati1, Mhairi Mackenzie2, David A. Ellis3, Michelle Major4, Kate O'Donnell1, Sharon Simpson [ID]5, Andrea Williamson [ID]1, Claire Duddy6, Geoff Wong [ID]6

1General Practice and Primary Care, University of Glasgow, Glasgow, Scotland, UK
2Urban Studies, University of Glasgow, Glasgow, Scotland, UK
3School of Management, University of Bath, Bath, England, UK
4Homeless Network Scotland, Glasgow, UK
5MRC/CSO Social & Public Health Sci Unit, University of Glasgow, Glasgow, Scotland, UK
6Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, England, UK

Abstract

Background

This protocol describes a realist review exploring the problem of "missingness" in healthcare, defined as the repeated tendency not to take up offers of care that has a negative impact on the person and their life chances. More specifically, the review looks at the phenomenon of patients missing multiple appointments in primary care in the UK – at the causal factors that influence how patients come to be "missing" in this way, and what interventions might support uptake and "presence" in healthcare. Background research informing this project suggests that a high rate of missed appointments predicted high premature death rates, and patients were more likely to have multiple long-term health conditions and experience significant socioeconomic disadvantage. Most research in this field focuses on population- or service-level characteristics of patients who miss appointments, often making no distinction between causes of single missed appointments and of multiple missed appointments. There have therefore been no interventions for 'missingness', accounting for the complex life circumstances or common mechanisms that cause people to repeatedly miss appointments.

Open Peer Review

Approval Status ？？

	1	2
version 1 22 Jun 2023	? view	? view

1. **Andrea Nederveld** [ID], University of Colorado, Denver, USA

2. **Kristina L Wanyonyi-Kay** [ID], THIS Institute University of Cambridge, Cambridge, UK

Any reports and responses or comments on the article can be found at the end of the article.

Methods

We use a realist review approach to explore what causes missingness - and what might prevent or address it - for whom, and in what circumstances. The review uses an iterative approach of database searching, citation-tracking and sourcing grey literature, with selected articles providing insight into the causal dynamics underpinning missed appointments and the interventions designed to address them.

Discussion

The findings of this review will be combined with the findings of a qualitative empirical study and the contributions of a Stakeholder Advisory Group (STAG) to inform the development of a programme theory that seeks to explain how missingness occurs, whom it affects and under what circumstances. This will be used to develop a complex intervention to address multiple missed appointments in primary care.

PROSPERO registration

CRD42022346006

Plain English summary

There are lots of reasons why patients might miss an appointment with their primary care provider. When someone misses *multiple* appointments, this is often a sign that they are experiencing barriers in accessing and engaging with the health system. This might also be a sign of wider difficulties someone is facing, and some research has connected multiple missed appointments to poverty, having multiple health conditions, and an increased risk of premature death. Proposed approaches to reducing missed appointments include text or phone reminders; reducing appointment waiting times; having walk-in surgeries; and fines or financial penalties for non-attendance. Their success is often measured from the perspective of the healthcare providers, and they often do not account for the experiences of patients - particularly those most at risk of missing multiple appointments and experiencing negative outcomes. With our limited understanding of who misses multiple appointments and why, we do not know what approaches are best to reduce multiple missed appointments and to help people access primary care.

This protocol describes how we will develop a theory to help explain why some people miss multiple primary care appointments. The theory will also explore what might work to reduce multiple missed appointments, for whom, and under what circumstances. We will search academic databases for existing research and combine this with other research evidence to help us explain these issues. We will combine this with data from interviews with people who have

experience of missing appointments, or supporting those who miss them, to build our theory. We will then use what we learn to design an intervention to reduce multiple missed appointments in primary care.

Keywords
Missed appointments, did not attend, realist review, primary care, failed appointments, missingness, protocol, non-attendance

Corresponding authors: Calum Lindsay (calum.lindsay@glasgow.ac.uk), David Baruffati (David.Baruffati@glasgow.ac.uk), Andrea Williamson (andrea.williamson@glasgow.ac.uk)

How to cite this article: Lindsay C, Baruffati D, Mackenzie M *et al.* **A realist review of the causes of, and current interventions to address 'missingness' in health care. [version 1; peer review: 2 approved with reservations]** NIHR Open Research 2023, **3**:33 https://doi.org/10.3310/nihropenres.13431.1

First published: 22 Jun 2023, **3**:33 https://doi.org/10.3310/nihropenres.13431.1

Plain English summary

There are lots of reasons why patients might miss an appointment with their primary care provider. When someone misses *multiple* appointments, this is often a sign that they are experiencing barriers in accessing and engaging with the health system. This might also be a sign of wider difficulties someone is facing, and some research has connected multiple missed appointments to poverty, having multiple health conditions, and an increased risk of premature death. Proposed approaches to reducing missed appointments include text or phone reminders; reducing appointment waiting times; having walk-in surgeries; and fines or financial penalties for non-attendance. Their success is often measured from the perspective of the healthcare providers, and they often do not account for the experiences of patients - particularly those most at risk of missing multiple appointments and experiencing negative outcomes. With our limited understanding of who misses multiple appointments and why, we do not know what approaches are best to reduce multiple missed appointments and to help people access primary care.

This protocol describes how we will develop a theory to help explain why some people miss multiple primary care appointments. The theory will also explore what might work to reduce multiple missed appointments, for whom, and under what circumstances. We will search academic databases for existing research and combine this with other research evidence to help us explain these issues. We will combine this with data from interviews with people who have experience of missing appointments, or supporting those who miss them, to build our theory. We will then use what we learn to design an intervention to reduce multiple missed appointments in primary care.

Introduction

This review is part of a wider project that aims to address multiple missed appointments and low uptake of care offers in health. It uses the term "missingness" to describe these patterns of low engagement (Williamson, 2021). In 2013, practitioners working in Scotland's most socio-economically deprived communities identified there was an important knowledge gap relating to who was missing from care (Watt, 2013). To address this gap, members of the project team produced a large-scale epidemiological study which found that health need was high and outcomes poor among those with patterns of multiple missed appointments in primary care (Ellis *et al.*, 2017; McQueenie *et al.*, 2019; McQueenie *et al.*, 2021; Williamson *et al.*, 2017; Williamson *et al.*, 2020; Williamson *et al.*, 2021). We define 'missingness' as the repeated tendency not to take up offers of care, such that it has a negative impact on the person and their life chances. Missing an average of two or more health appointments per year was associated with significant socioeconomic disadvantage and correlated with patients having multiple health conditions (particularly mental health) and a range of other factors suggesting a complex causal link between social and health inequalities and missingness (Ellis *et al.*, 2017; Williamson *et al.*, 2020).

Existing work around missed appointments has described the characteristics of patients who miss appointments, connecting demographic information to the likelihood of a patient missing an appointment. Previous literature reviews suggest that patients who miss appointments are likely to be younger and to come from more economically-deprived communities (Dantas *et al.*, 2018; Finlayson *et al.*, 2016; George & Rubin, 2003; Parsons *et al.*, 2021). Patients who have previously missed appointments are more likely to miss appointments in future (Dantas *et al.*, 2018; Parsons *et al.*, 2021). Where research has sought qualitative insights into missed appointments from patients and healthcare practitioners, reasons have included: patients forgetting; other commitments or personal circumstances precluding attendance; or practical considerations including transportation (Neal *et al.*, 2005; Wilson & Winnard, 2022). There has been limited distinction in this literature between missing one appointment and missing many – between a missed appointment as a discrete event, and "missingness" as a specific phenomenon with specific causes and effects.

The problem of missed appointments is often framed in terms of wasted time and money for the NHS or waiting lists and barriers for other patients (NHS Borders, 2016; NHS England, 2019a). Those who miss appointments are often framed as irresponsible, or as people making an active choice to be absent and therefore less needful of primary care (Husain-Gambles *et al.*, 2004; NHS England, 2019b). Where the problem is simply a matter of reducing missed appointments in general, interventions are often generic and aimed at the general practice population. There is a connected body of research focused on evaluating interventions including mobile phone reminders to manage forgetfulness (Gurol-Urganci *et al.*, 2013), behavioural interventions to promote responsible patient behaviour (Bull *et al.*, 2023; Martin *et al.*, 2012), or predictive scheduling systems to reduce wasted resources (Ahmad *et al.*, 2021). These papers rarely make the distinction between single and multiple missed appointments, and do not interrogate the deeper causal dynamics that underpin the challenges faced by some patients in taking up offers of care. We also have a poor understanding of the lived experience of 'missingness' in care and hence why people may be missing from one or more service.

Without explicitly targeting interventions at "missingness" in a way that accounts for patients' complex life circumstances and the causal mechanisms that impact engagement across services, we hypothesise that those in greatest need of healthcare assistance are least likely to access it. For many interventions there may be an inverse care effect, either excluding or actively deterring those most in need of support to access and engage with healthcare (Smith *et al.*, 2022). The area of *multiple* missed appointments is under-researched and under-theorised, and there is a need for a more nuanced and careful consideration of the causal mechanisms for missing appointments and the ways in which attendance might be increased. There are some small local initiatives exploring how to increase engagement in health and care services in the UK and beyond, but they tend to be piecemeal and targeted at specific patient groups, such as patients experiencing homelessness (e.g Finlayson *et al.*, 2016; Watt, 2013). In such a complex area, it is difficult to prove or disprove causality as the underlying causal mechanisms are complex, interconnected, influenced by wider social determinants of health, and with a differential

impact on people in different social circumstances. We hypothesise that there may be common underlying factors and therefore common strategies that will support engagement and increase health and wellbeing for those at highest risk.

A realist approach

By understanding missingness as an under-theorised problem with complex causal underpinnings that affects a range of people across multiple services, we felt a realist review was a suitable approach. Realist review is a theory-driven approach to evidence synthesis that seeks to explain the causal dynamics of social phenomena (Pawson, 2006). It explores how interventions work, for whom, and in what contexts they produce their outcomes. A realist analytical approach is applied to data drawn from a range of sources, including primary research of any study design and non-academic 'grey' literature. The purpose of the analysis is to produce a programme theory – "[a] description […] of what is supposed to be done in a policy or programme (theory of action) and how and why that is expected to work (theory of change)" (Greenhalgh et al., 2017). A realist programme theory consists of several Context-Mechanism-Outcome configurations (CMOCs). These CMOCs explain the relationship between the context or circumstances around a person, the underlying causal mechanisms at play, and the intended or unintended outcomes their interactions produce (ibid). This protocol outlines the development of a realist review of secondary data. This data will be integrated with primary data gathered through realist interviews and through the input of a stakeholder advisory group to refine our programme theory and inform the development of a complex intervention.

Aims, objectives and research questions

The aim of this project is to develop a theoretically-informed understanding of 'missingness' from patient, professional and policy perspectives with the intent of co-producing a complex intervention with multiple components for primary care to test in a future study. This will occur in three work-packages (WP): the realist review outlined in this protocol (WP1); a series of realist interviews with experts-by-experience and practitioners and other professional participants (WP2); and by convening a Stakeholder Advisory Group to guide the process, refine the emerging programme theory and devise an intervention to address "missingness" in primary care (WP3). The research design follows the new MRC Complex interventions Framework (Skivington et al., 2021) and the INDEX guidance (O'Cathain et al., 2019) on development of an intervention. This will be achieved by; identifying the evidence base (WP1 and 2); identifying and developing the programme theory (WP1-3) and qualitatively modelling process and outcomes using participatory methods and co-design (WP3). We will utilise the 6SQuID method of intervention development explicitly (Wight et al., 2016).

This protocol only describes WP1, which has 2 main research questions:

- Research question 1: What is known already in the health, social care and voluntary sector literature about the causes of 'missingness' in health care?

- Research question 2: What do we know from the literature about interventions which aim to address 'missingness' in health care?

Methods
Patient and Public Involvement

Patient and Public Involvement is central to the study background and design. In developing the research that underpins this study, members of the research team consulted the Royal College of GPs Scotland Patient Participation in Practice (P3) group in 2016. The group described patient narratives they had come across around 'missingness' and agreed that the area was under-researched and important, producing a written letter of support for the subsequent epidemiological study. During the conceptualisation phase of this project, Williamson led a small unpublished pilot project interviewing 6 practitioners in the voluntary sector and people with lived experience of 'missingness' about their experience. Participants felt that 'missingness' was a distinct, recognisable and important issue for patients and for services and suggested some ways of addressing it. A previous public Co-Investigator with experience of working with people with severe and multiple disadvantage was involved in developing the subsequent Stage 1 and Stage 2 NIHR funding proposal with a particular focus on engaging people with lived experience. The current Public Co-Investigator (Major) is employed by Homeless Network Scotland and will contribute to full-team meetings to review progress, provide input on recruitment, data collection and analysis and will help steer dissemination of outputs.

We are convening a Stakeholder Advisory Group (StAG) of experts-by-experience of as well as practitioners in key service areas. The StAG will meet at key times during the project, initially as a small group of 4 experts-by-experience and 4 professionals. This group will contribute to the development and the refinement of the programme theory during the realist review. In Work Package 3, we will convene a larger group of 8 experts-by-experience and 8 professionals to support intervention development, shaping the output of the study and plans for dissemination. Experts by experience and practitioners are also the central focus of our qualitative interviews in Work Package 2 which will provide data for theory and intervention development.**Methods**

Within a realist review, the process of searching, screening and analysing relevant material is iterative and cyclical (see Figure 1). Rather than seeking out an exhaustive view of all available literature within a single search, or restricting to specific types of research, the realist approach is inclusive, with papers selected for how far they might advance the development and refinement of the programme theory until "theoretical saturation" is achieved - when "'sufficient evidence is found such that it is reasonable to claim that the theory is coherent and plausible" (Wong et al., 2013 cited in Duddy & Roberts, 2022). The proposed iterative approach for this project is shown in Figure 2 below.

We carried out an initial scoping search of MEDLINE and Web of Science (Science and Social Science Citation indexes) in January 2022 to inform the conceptualisation phase of the
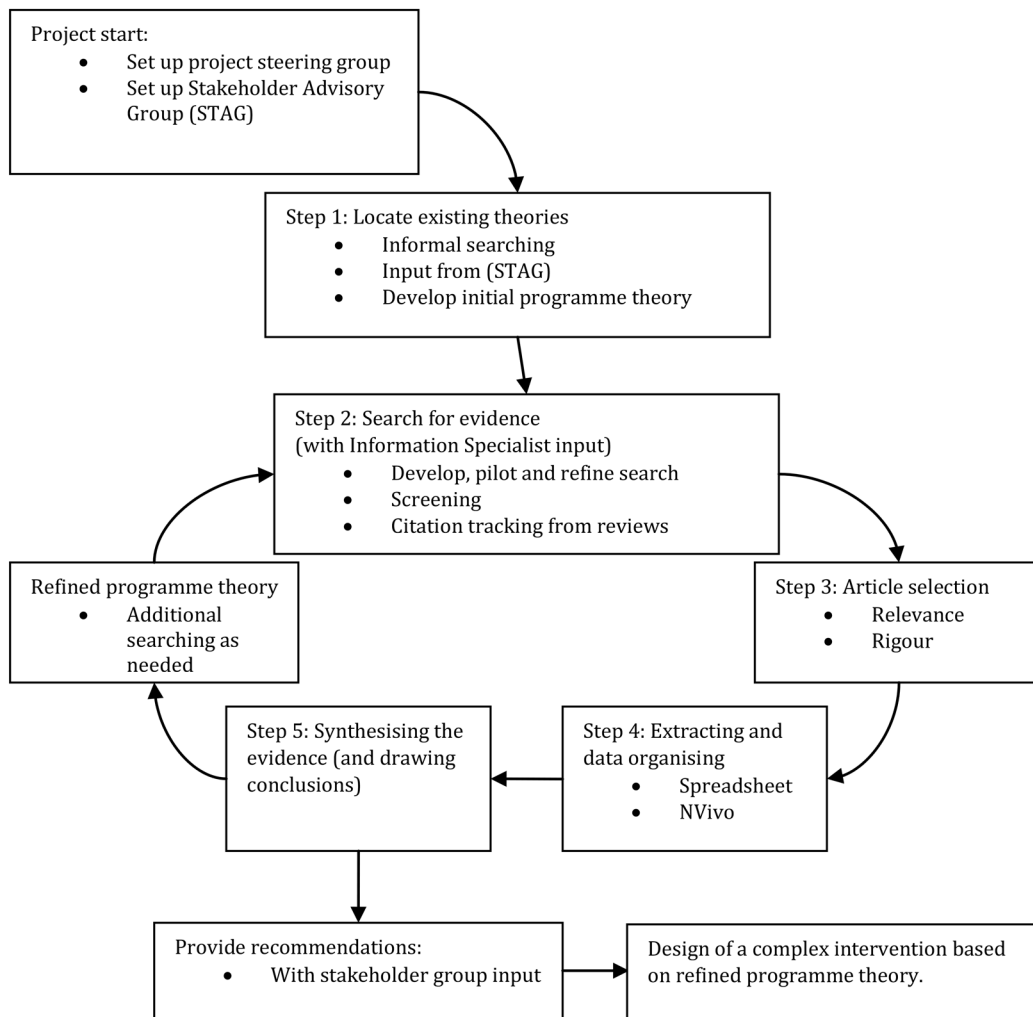
```
┌─────────────────────────────────┐
│ Project start:                  │
│   •  Set up project steering    │
│      group                      │
│   •  Set up Stakeholder Advisory│
│      Group (STAG)               │
└─────────────────────────────────┘
```

Step 1: Locate existing theories
- Informal searching
- Input from (STAG)
- Develop initial programme theory

Step 2: Search for evidence
(with Information Specialist input)
- Develop, pilot and refine search
- Screening
- Citation tracking from reviews

Refined programme theory
- Additional searching as needed

Step 3: Article selection
- Relevance
- Rigour

Step 5: Synthesising the evidence (and drawing conclusions)

Step 4: Extracting and data organising
- Spreadsheet
- NVivo

Provide recommendations:
- With stakeholder group input

Design of a complex intervention based on refined programme theory.

Figure 1. Realist Review process (adapted with permission from Wong *et al.*, 2015).

project using keywords describing repeated missed appointments, low engagement/uptake and attendance in healthcare to explore the available existing literature. Through further exploratory and informal searching an initial programme theory was created, shaped around the candidacy framework (Dixon-Woods *et al.*, 2006; Mackenzie *et al.*, 2019) as an initial theoretical/conceptual frame. This framework suggests that "missingness" is an expression of inequalities in access to, and utilisation of, health services. It provides a heuristic framework for moving beyond simplistic ideas of access to understand service engagement as a journey, one that proceeds in several connected and non-linear stages. Our initial programme theory suggests that dynamics within and between stages of this process influence whether a person becomes "missing":

- **Identification:** some patients may not view themselves as legitimate and worthy candidates for primary care, or may feel the support provided is not for them or will not benefit them.

- **Navigation:** patients may have limited resources to overcome practical barriers including travel costs, phone credit, limited knowledge of how to navigate systems, or multiple and competing life priorities that are hard to prioritise.

- **Permeability and porosity:** GP services may be difficult to access – inflexible appointment times or systems, long waits for appointments, gatekeeping practices, no choice of clinicians or no access to additional support – that are poorly aligned with the resources or preferences of patients.

- **Presentation:** The act of presenting to general practice may be less of a priority in complex life circumstances. Poor physical or mental health my inhibit to ability to attend, while patients may experience difficulties communicating or being heard in appointment spaces. Prior experiences of stigma or exclusionary practice

may inhibit or constrain people's willingness or ability to present.

- **Adjudication:** where practitioners make judgements about patients' health, often these can stigmatise or feel exclusionary and limit future engagements. GP service dynamics may mean adjudications are made on heuristics, categorisations and moral schemas of staff, and there is limited space for trusted relationships to be formed or maintained.

- **Offers and resistance:** Problems in adjudication can mean the offers made to patients do not meet their hopes or expectations and can inhibit future engagement with services. Often, services view such non-engagement as patient negligence or choice rather than a form of resistance or negotiation that could be addressed by providing care through a "missingness" lens.

- **Local operating conditions:** the resourcing and context of service provision may prevent identification of patients at risk of "missingness", may create narrow routes for access and inhibit presentation and adjudication. Professional practice may not meaningfully account for those who are "missing" and respond with support or improved practice (see Dixon-Woods *et al*., 2006).

The framework will likely be complemented by other substantive theories in health inequalities, including structural vulnerability (Quesada *et al*., 2011), fundamental cause theory (Phelan & Link, 2013) and other theories that speak to the causal dynamics underpinning the candidacy process.

Strategy for an initial search: Following our informal exploration of the literature, the team's information specialist (Duddy) carried out initial test searches that returned a large volume of diverse literature that could be considered for inclusion in the review. We identified 15 "core" papers against which searches could be benchmarked and on which they could be based. The initial strategy was to outline specific population groups we anticipated would be most relevant (people with Adverse Childhood Experiences; people experiencing severe and multiple disadvantage such as homelessness, problem substance use, mental health issues; people with cognitive impairment; young people in the care system; people with multi-morbidity, as well as others who repeatedly or persistently miss appointments or opportunities to receive care). Adding these terms, we found a significant increase in the number of records returned without necessarily achieving greater relevance, and numbers exceeded what could be screened by a single researcher within the project timescale. Attempts to narrow the search terms to exclusively focus on repeat or multiple missed appointments had the opposite effect and resulted in only 3 of the 15 "core papers" being returned, suggesting (later confirmed by abstract review) that few papers made the distinction between single and multiple missed appointments explicit outside the full text. Searches were based on a combination of free text and subject heading (e.g. MeSH) terms describing missed opportunities for care.

To balance breadth and specificity in the initial search, a comprehensive set of terms describing missed opportunities for care were employed, but limited to the title field (and focused subject headings, where applicable). These terms were combined with two search filters, one describing primary health care and one to identify material focused on UK settings. These were adapted for use across databases. The search strategy was developed and piloted in Ovid MEDLINE and subsequently translated and run across Embase (Ovid), PsycINFO (Ovid), HMIC (Ovid), CINAHL (EbscoHost) and Web of Science (SCIE and SSCI indexes).

Citation-tracking: Our scoping searches also identified several existing reviews of the literature on missed appointments, non-attendance and non-engagement with health care services. These reviews cover a range of settings and research questions, exploring both potential causes and solutions to these problems. To avoid duplicating the work already embodied in these reviews, we considered both the reviews themselves and the studies included within them for inclusion in our realist review. Our strategy therefore combined the initial search of six databases described above with citation tracking from a set of six recent review papers (Amberger & Shreyer, 2022; Dantas *et al*., 2018; George & Rubin, 2003; Parsons *et al*., 2021; Sun *et al*., 2021; Wilson & Winnard, 2022). Project team members were also aware of relevant 'grey literature' that could provide additional data for the review, including policy documents, research reports, and service evaluations. At this stage, the included grey literature is minimal. If required, future strategies to secure grey literature include searching ETHOS (British Library Electronic Thesis Online), ProQuest Dissertations and Theses, OpenGrey (System for Information on Grey Literature in Europe), the King's Fund Library Database, and NHS Knowledge and Library. We will also draw on established links with the Revolving Doors Agency, Lankelly Chase, professional networks (Royal College of GPs Health Inequalities Standing Group UK, Faculty for Homeless and Inclusion Health UK, North American Primary Care Research Group Homelessness Special Interest Group, Doctors of the World) and relevant NHS organisations to identify additional literature.

We anticipate that the literature returned in these initial searches will return a significant amount of literature for the development and refinement of our programme theory. Once it has been analysed, we will carry out additional searches (Searches C, D and E in Figure 2) if required to further refine our theories or to address additional knowledge gaps that emerge in screening and analysis (Duddy & Roberts, 2022). These searches will support the conceptual and contextual richness of the evidence base we draw upon. We will also carry out additional citation-tracking and gathering of further related papers in key conceptual, theoretical or empirical areas. The interview study and STAG group are also essential to building on the existing (and limited) research base and identifying further areas for searching. This will continue until we judge that the refined programme theory is sufficiently coherent and plausible (Wong *et al*., 2013).
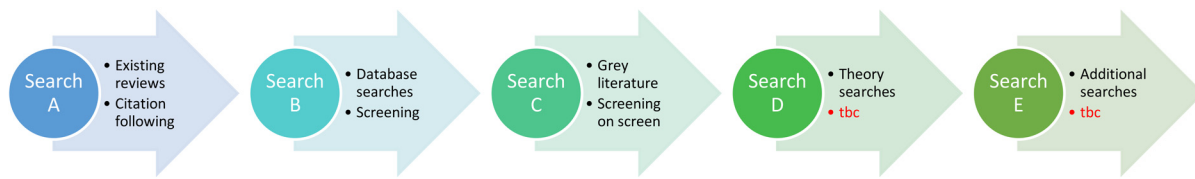
Figure 2. Stages of searching.

Selection and appraisal: Results from the database search and citation-tracking were exported and uploaded to separate EndNote files and deduplicated. The final results were combined, deduplicated again, and uploaded to DistillerSR software for screening. Titles and Abstracts were screened against a single, narrow question: "does the paper provide insights into missed appointments in NHS primary care?" Because of the iterative nature of the project, excluded material was labelled and placed into 'pots' for possible future consideration, distinguishing between:

- Studies in the NHS not relevant to appointments in primary care (typically outpatient or specialist settings, or screening programs).

- Studies on primary care in other locations, with studies labelled to allow future searching of locations – particularly those akin to the NHS, where healthcare is free at the point of use.

- Studies on missed appointments in non-healthcare settings in the UK.

- Studies of missed appointments not relevant to primary care and based in countries other than the UK.

Studies that did not fit into these 'pots' were excluded outright. Where important data were unclear (e.g. where locations or settings were not specified in the title or abstract), they were included for full-text screening. Full-text screening was carried out by Lindsay according to the same question, with studies excluded outright, relabelled to fit into the pots above, or labelled as possible studies of interest at later stages of the project. A 10% random sample was checked by Wong at both title/abstract screening and full-text screening with disagreements resolved through discussion and refinement of inclusion/exclusion criteria to ensure consistency.

A PRISMA diagram outlines the progress of data extraction (work in progress as of April 2023) from Search A and Search B is available. This is included in the *Extended data* (Ellis *et al*., 2023).

Data extraction and analysis
Lindsay will carry out two forms of data extraction. The first is descriptive data extraction to gather the key characteristics of papers will be carried out in Microsoft Excel. Full-text papers will be uploaded to NVivo to assist data analysis. Relevant sections of text that the reviewer sees as relevant to understanding contexts, mechanisms and their relationship to outcomes will be coded in Nvivo. The coding

process involves inductive coding of data from within the included studies and deductive coding in line with existing codes informed by the initial programme theory. Coding also involves abduction, with parameters influenced by emerging theoretical understandings while those understandings themselves are shaped by the empirical data to find logical, useful and plausible solutions to the presenting problems (Thompson, 2022). Retroductive coding will also be used to support the interpretation of data to infer the hidden causal forces underpinning the outcome of "missingness" or the outcomes of interventions to address missed appointments. Each relevant piece of data will be used to refine the programme theory and as the theory is refined included studies will be re-scrutinised to identify data that may have been missed initially (Wong *et al*., 2013). Analysis will include the following analytical judgements:

- Relevance: do sections of data within the document have relevance for development or refinement of the programme theory?

- Rigour and trustworthiness: are the data sufficiently trustworthy and plausible, and are they beneficial at the level of the programme theory.

- Analytical interpretations about CMOCs, including what the data says about what is functioning as contexts, mechanisms and outcomes and how these relate to each other to form emerging CMOCs.

- Assessments of what these data say about the relationships of the CMOCs and programme theory and how it might be altered or refined.

Synthesis of data about contexts, mechanisms and outcomes within and between documents will be required because full configurations will rarely be available within a single source. Cross-comparison, contrast, identification of outlying or contradictory data will also support exploration of deep causal dynamics (Martin, 2020). For example, exploring where interventions have been 'successful' in some areas and not others, or for some groups and not others, supports an understanding of contextual dynamics. Where possible secondary data from the review will be analysed alongside primary data, with each supporting the refinement of the emerging programme theory and the CMOCs within it.

Discussion and future directions
Ultimately, the analysis that emerges from this process will inform which practical intervention strategies we might be able to use in WP 3, as the programme theory will suggest

key mechanisms that might be triggered and key contextual factors that might be changed to produce our desired outcome – addressing missingness in primary care encounters. Intervention development will follow the 6SQuID method, a six-stage model developing complex interventions (Wight *et al.*, 2016). Data from Work Package 1 (realist review) and 2 (realist interview) will be used to address steps 1–3 of the 6SQuID process:

- 1. Define the problem and its causes.

- 2. Explore which causal or contextual factors are malleable and have the most potential for change.

- 3. Identify how to bring about change (i.e. the change mechanism(s)).

The Stakeholder Advisory Group will be convened to develop the intervention, consisting of 16 members including 8 experts-by-experience and 8 key professionals. Through four half-day workshops, the group will support development of a complex intervention to reduce "missingness" in primary care.

Data availability

Underlying data
No underlying data are associated with this article.

Extended data
Open Science Framework: Developing interventions to reduce 'missingness' in health care

https://doi.org/10.17605/OSF.IO/E4BDV (Ellis *et al.*, 2023)

The project contains the following extended data:

- Medline search strategy.xlsx

- Missingness – PRISMA 19.4.23.pdf

- PRISMA-P-checklist 19.4.23.pdf

Data are available under the terms of the Creative Commons Attribution 4.0 International license (CC-BY 4.0).

Software availability statement
The software used on this project is proprietary but free alternatives are available for the following:

Endnote: has a free version, and alternatives include Mendeley or Zotero

DistillerSR: is proprietary software but free alternatives include Colandr or Abstrackr

Excel: is proprietary software but can be used for free in its online version. Google Sheets is an alternative.

Nvivo is proprietary software but alternatives include Taguette.

References

Ahmad MU, Zhang A, Mhaskar R: **A predictive model for decreasing clinical no-show rates in a primary care setting.** *Int J Health Policy Manag.* 2021 predictive, 2021; **14**(3): 829–836.
Publisher Full Text

Amberger C, Schreyer D: **What do we know about no-show behavior? A systematic, interdisciplinary literature review.** *J Econ Surv.* 2022.
Publisher Full Text

Bull SL, Frost N, Bull ER: **Behaviourally informed, patient-led interventions to reduce missed appointments in general practice: a 12-month implementation study.** *Fam Pract.* 2023; **40**(1): 16–22.
PubMed Abstract | **Publisher Full Text**

Dantas LF, Fleck JL, Cyrino Oliveira FL, *et al.*: **No-shows in appointment scheduling - a systematic literature review.** *Health Policy.* 2018; **122**(4): 412–421.
PubMed Abstract | **Publisher Full Text**

Dixon-Woods M, Cavers D, Agarwal S, *et al.*: **Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups.** *BMC Med Res Methodol.* 2006; **6**: 35.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Duddy C, Roberts N: **Identifying evidence for five realist reviews in primary health care: A comparison of search methods.** *Res Synth Methods.* 2022; **13**(2): 190–203.
PubMed Abstract | **Publisher Full Text**

Ellis DA, Lindsay C, Duddy C: **Developing interventions to reduce 'missingness' in health care.** 2023.
http://www.doi.org/10.17605/OSF.IO/E4BDV

Ellis DA, McQueenie R, McConnachie A, *et al.*: **Demographic and practice factors predicting repeated non-attendance in primary care: a national retrospective cohort analysis.** *Lancet Public Health.* 2017; **2**(12): e551–e559.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Finlayson S, Boelman V, Young R, *et al.*: **SAVING LIVES, SAVING MONEY How Homeless Health Peer Advocacy Reduces Health Inequalities.** *Groundswell.*

2016.
Reference Source

George A, Rubin G: **Non-attendance in general practice: a systematic review and its implications for access to primary health care.** *Fam Pract.* 2003; **20**(2): 178–184.
PubMed Abstract | **Publisher Full Text**

Greenhalgh T, Pawson R, Wong G, *et al.*: **'Theory' in Realist Evaluation The Rameses II project.** 2017.
Reference Source

Gurol-Urganci I, de Jongh T, Vodopivec-Jamsek V, *et al.*: **Mobile phone messaging reminders for attendance at healthcare appointments.** *Cochrane Database Syst Rev.* 2013; **2013**(12): CD007458.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Husain-Gambles M, Neal RD, Dempsey O, *et al.*: **Missed appointments in primary care: questionnaire and focus group study of health professionals.** *Br J Gen Pract.* 2004; **54**(499): 108–13.
PubMed Abstract | **Free Full Text**

Mackenzie M, Gannon M, Stanley N, *et al.*: **'You certainly don't go back to the doctor once you've been told, "I'll never understand women like you."' Seeking candidacy and structural competency in the dynamics of domestic abuse disclosure.** *Sociol Health Illn.* 2019; **41**(6): 1159–1174.
PubMed Abstract | **Publisher Full Text**

Martin L: **Critical realism in theory and practice.** *Qualitative analysis: Eight approaches for the social sciences.* 2020; 155–70.

Martin SJ, Bassi S, Dunbar-Rees R: **Commitments, norms and custard creams–a social influence approach to reducing did not attends (DNAs).** *J R Soc Med.* 2012; **105**(3): 101–4.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

McQueenie R, Ellis DA, Fleming M, *et al.*: **Educational associations with missed GP appointments for patients under 35 years old: administrative data linkage study.** *BMC Med.* 2021; **19**(1): 219.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

McQueenie R, Ellis DA, McConnachie A, *et al.*: **Morbidity, mortality and missed appointments in healthcare: a national retrospective data linkage study.** *BMC Med.* 2019; **17**(1): 2.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Neal RD, Hussain-Gambles M, Allgar VL, *et al.*: **Reasons for and consequences of missed appointments in general practice in the UK: questionnaire survey and prospective review of medical records.** *BMC Fam Pract.* 2005; **6**: 47.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

NHS Borders: **Going to miss your appointment? Let us know and we'll give it to someone else.** 2016.
Reference Source

NHS England: **NHS Long Term Plan.** 2019a.
Reference Source

NHS England: **Missed GP appointments costing NHS millions.** UK: NHS England; 2019b.
Reference Source

O'Cathain A, Croot L, Duncan E, *et al.*: **Guidance on how to develop complex interventions to improve health and healthcare.** *BMJ Open.* 2019; **9**(8): e029954.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Parsons J, Bryce C, Atherton H: **Which patients miss appointments with general practice and why? A systematic review.** *Br J Gen Pract.* 2021; **71**(707): e406–e412.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Pawson R: **Evidence-Based Policy: A Realist Perspective.** UK: Sage; 2006.
Reference Source

Phelan JC, Link BG: **Fundamental cause theory.** *Medical sociology on the move: New directions in theory.* 2013; 105–25.
Publisher Full Text

Quesada J, Hart LK, Bourgois P: **Structural Vulnerability and Health: Latino Migrant Laborers in the United States.** *Med Anthropol.* 2011; **30**(4): 339–62.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Skivington K, Matthews L, Simpson SA, *et al.*: **A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance.** *BMJ.* 2021; **374**: n2061.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Smith M, Vaughan Sarrazin M, Wang X, *et al.*: **Risk from delayed or missed care and non-COVID-19 outcomes for older patients with chronic conditions during the pandemic.** *J Am Geriatr Soc.* 2022; **70**(5): 1314–1324.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Sun CA, Taylor K, Levin S, *et al.*: **Factors associated with missed appointments by adults with type 2 diabetes mellitus: a systematic review.** *BMJ Open Diabetes Res Care.* 2021; **9**(1): e001819.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Thompson J: **A guide to abductive thematic analysis.** *Qualitative Report.* 2022; **27**(5): 1410–1421.
Publisher Full Text

Watt G: **Deep End Report 19. Access to Specialists. The 19th meeting of 'General Practitioners at the Deep End'.** University of Glasgow; 2013.
Reference Source

Wight D, Wimbush E, Jepson R, *et al.*: **Six steps in quality intervention development (6SQuID).** *J Epidemiol Community Health.* 2016; **70**(5): 520–5.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Williamson AE, Ellis DA, Wilson P, *et al.*: **Understanding repeated non-attendance in health services: a pilot analysis of administrative data and full study protocol for a national retrospective cohort.** *BMJ Open.* 2017; **7**(2): e014120.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Williamson AE, McQueenie R, Ellis DA, *et al.*: **'Missingness' in health care: Associations between hospital utilization and missed appointments in general practice. A retrospective cohort study.** *PLoS One.* 2021; **16**(6): e0253163.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Williamson AE, McQueenie R, Ellis DA, *et al.*: **General practice recording of adverse childhood experiences: a retrospective cohort study of GP records.** *BJGP Open.* 2020; **4**(1): bjgpopen20X101011.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Williamson AE: **Missingness in health care- a 'new normal' is not a level playing field.** UK: Royal College of General Practitioners; [05/05/2021]. 2021.
Reference Source

Wilson R, Winnard Y: **Causes, impacts and possible mitigation of non-attendance of appointments within the National Health Service: a literature review.** *J Health Organ Manag.* 2022; **36**(7): 892–911.
PubMed Abstract | **Publisher Full Text**

Wong G, Brennan N, Mattick K, *et al.*: **Interventions to improve antimicrobial prescribing of doctors in training: the IMPACT (IMProving Antimicrobial presCribing of doctors in Training) realist review.** *BMJ Open.* 2015; **5**(10): e009059.
PubMed Abstract | **Publisher Full Text** | **Free Full Text**

Wong G WG, Pawson R, Greenhalgh T: **Realist Synthesis. RAMESES Training Materials. RAMESES Project.** 2013.
Reference Source

Open Peer Review

Current Peer Review Status: ❓ ❓

Version 1

Reviewer Report 22 April 2024

https://doi.org/10.3310/nihropenres.14568.r31237

❓ **Kristina L Wanyonyi-Kay** (iD)

THIS Institute University of Cambridge, Cambridge, England, UK

This protocol describes a realist review on missing multiple appointments in primary care in the UK. This review informs a wider study to design a complex intervention to address the same subject. The review answers two questions
1.what causes a patient to be "missing" in this way, and 2.what interventions might support uptake and "presence" in healthcare.
The introduction rationalizes the project, pointing out the poor outcome related to missing appointments and also identifies the potential groups of patients who would be missing.
It is however unclear in many parts whether there are age related differences. For example in the second paragraph of the introduction 3rd line it is said that the patients tend to be younger. It is unclear as to what this means, younger compared to ? or is it young adults?. In which case the distinction in agency between young and older patients missing appointments would be something worth addressing.
The methodology as far as a realist review go appear sound. It is however unclear to report some of the initial /pilot/scoping search results within the protocol while outlining future work. This makes it a little difficult to follow. In some ways these findings related to causal theories are described at the expense of more detail related to the second question related to existing interventions. This is indeed an interesting project, but authors will want to consider if they would prefer to outline the process only or process of the whole project sans the scoping findings.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health service research

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 24 November 2023

https://doi.org/10.3310/nihropenres.14568.r30162

?
Andrea Nederveld (iD)

University of Colorado, Denver, Colorado, USA

This article outlines a pilot of a realist review of "missingness" in healthcare as well as the protocol for a full realist review that the authors will conduct as part of a larger project. They provide the background for this project, which is that there is good evidence that people who multiple opportunities for needed healthcare likely have worse overall outcomes and are likely prevented from accessing care due to difficult life circumstances. They provide some preliminary conclusions based on a pilot of their search strategy and review of the literature. The initial results are very interesting and certainly address an important and relevant problem. However, I think consideration should be given to whether it is valuable to publish this at the current stage, or to wait and publish the completed review. This paper may be more effective and efficient as a protocol for the entire project rather than a partial review of the literature when they plan to do a complete review as the first stage of the project.

Is the rationale for, and objectives of, the study clearly described?
Yes

Is the study design appropriate for the research question?
Yes

Are sufficient details of the methods provided to allow replication by others?
Yes

Are the datasets clearly presented in a useable and accessible format?
Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Primary care, underserved population, social needs, health services.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 28 Nov 2023

Calum Lindsay

Hi Andrea,

Thanks so much for taking the time to review our protocol paper. We fully agree that it's important to provide the full and detailed findings of the whole study and hope to have papers published in the next few months. We published the protocol in its current form for two main reasons. Firstly, it allows others to know what work is ongoing in this field. It also helps us provide a detailed outline of our methods, which will be much shorter in future papers - a reference point for readers while allowing us to focus on our findings in future. Let me know if you have any thoughts or questions on this - happy to address any queries you might have.

All the best,

Calum

Competing Interests: n/a