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Social Media in Health and Care

Co-production

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Doctor of Philosophy

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Declaration

I declare that this thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text, and that this work has not been submitted for any other degree or professional qualification except as specified.

Hadi Daneshvar

25th Oct 2019 - Edinburgh

This thesis includes content from the following published papers:

- 1- How Can Current Social Media Lead to Co-production (Co-Delivery) of New Services? A Qualitative Study, H. Daneshvar, S. Anderson, R. Williams and H. Mozaffar, JMIR Hum Factors 2018; 5(1):e5, DOI: 10.2196/humanfactors.7856
- 2- The Impact of Social Media on Reshaping of Healthcare Delivery for Elderly People: The Intended and Unintended Consequences, Pre ECIS-Workshop: New Technologies, Organisations and Work, Portsmouth, the UK, June 2018
- 3- Challenges and Opportunities of Health and Care Co-production with Social Media: a Qualitative Study. 6th International Workshop on Infrastructures for Healthcare: Infrastructures for governance, quality improvement and service efficiency, Aarhus, Denmark, June 2017
- 4- How Existing Social Media Assist Health and Care Co-production: a Qualitative Study? MCCSIS 2016, Madeira, Portugal, 1- 3 July 2016
- 5- Can Existing Social Media Encourage Health and Care Co-production? BCS Health Informatics Scotland 2015, Edinburgh, the UK, 7-8 October 2015

- 6- Social Media in Health and Care with Co-production in Future – Medicine 2.0'14 Europe, Malaga, Spain 9 October 2014
- 7- Future of Social Media in Health and Care with Co-production – International Digital Health and Care Congress, Kings Fund 2014, London, the UK, 11 September 2014
- 8- Co-production of Health and Care through use of Social Media – poster presentation and present in SICSA PhD Conferences and HCI Doctoral Consortium 2014, St Andrews University, the UK, 9-10 June 2014

Abstract

The future of health and care services in the EU faces the three challenges of the aging population, fiscal restriction, and social inclusion. Co-production offers ways to manage informal care resources to enable them to better cater to the growing needs of elderly people. Social Media (SM) are seen as a critical enabler of co-production.

This study investigates SM as an enabler of co-production in health and care for elderly people and develops a typology of opportunities and limitations of SM in relation to health and care. The study considers how SM acts as an enabler of co-production in health and care by facilitating its four underlying principles: equality, diversity, accessibility, and reciprocity. Normalization Process Theory (NPT) provides the theoretical framework for this qualitative study. Eighteen semi-structured interviews and observation of the activities of 10 online groups and individuals provide the data for the thematically-analysed findings.

The study findings show how different SM are used to enable co-production through coordination and communication across boundaries. SM connects carers, disseminates information and engages volunteers. However, many types of SM are only rarely used in this sector due to their limitations. Nevertheless, carers of elderly patients demonstrated interest in using systems to engage people in the shaping of services, the sharing of experiences and encouraging activities. The study findings point to distinct patterns of feature use by different people involved in the care of elderly people. This diversity makes possible the principles of co-production by offering equality among users, enabling diversity of use, making experiences accessible, and encouraging reciprocity in the sharing of knowledge and mutual support. Exploitation of common resources also may lead to new forms of competition and conflicts. These conflicts require better management to enhance the coordination of the common pool of resources.

The study finds that SM can facilitate co-production by offering mechanisms for coordination of the common pool of carer resources. It also enables better management of activities amongst other actors (professionals, patients, voluntary organisations, etc.). The study also demonstrates that, despite the capabilities of SM in achieving co-production, many applications (both general and healthcare-specific) are not used to

their full potential. The study also explores new innovations in this field and why they have failed to deliver their intended services.

In the name of God

the most compassionate the most merciful

I dedicate this work to my family who I love the most,

The love of my life Kajar,

My beautiful angles Mahdis and Sama

&

In the memory of my beloved Mother and Father

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Abbreviations

AAL	-	Active and Assisted Living Programme
ADL	-	Activities of Daily living
AI	-	Artificial Intelligence
ANT	-	Actor Network Theory
BLF	-	British Lung Foundation
CPR	-	Common Pool Resources
CMS	-	Content Management System
DALLAS	-	Delivering Assisted Living Lifestyles At Scale
EU	-	European Union
FBG	-	Facebook Group
GP	-	General Practitioner
HCIS	-	Hospital Computer Information System
HIE	-	Highlands and Islands Enterprise
HLE	-	Healthy Life Expectancy
ICT	-	Information Communication Technology
IM	-	Instant Messaging
IT	-	Information Technology
LE	-	Life Expectancy
LET	-	Life Enhancing Technology
LiU	-	Living it Up
LTC	-	Long-Term Care
MI	-	More Independent
NHS	-	National Health System
NPT	-	Normalisation Process Theory
PCHR	-	Personal Child Health Record
QoL	-	Quality of Life
RCPCH	-	The Royal College of Paediatrics and Child Health
SM	-	Social Media
SMS	-	Social Network Sites
SST	-	Strong Shaping of Technology
TMIS	-	Technicon Medical Information System
UK	-	United Kingdom

Table of content

Declaration	iii
Abstract	v
Acknowledgements	vii
Abbreviations	x
Table of content	xi
List of tables	xvii
List of figures	xix
Chapter 1- Introduction	1
1.1 Context	1
1.2 Research aims and questions	5
1.3 Outline of the dissertation	6
Chapter 2 - Literature Review	9
2.1 Introduction	9
2.1 Aging population.....	9
2.2 A brief history of Information and Communication Technology (ICT) use in health and care.....	12
2.3 Defining health, care and ICT for health and care	13
2.3.1 What is care.....	14
2.3.2 What is social care?.....	15
2.3.3 Who is the carer	16
2.3.4 Value of carers in the UK.....	17
2.3.5 Health care	18
2.3.6 Integration of health and social care	18
2.4 Co-production.....	19
2.4.1 The history of co-production.....	20
2.4.2 Types of co-production	21
2.4.3 Asset-based Approach.....	22
2.4.4 Benefits and problems in co-production	22

2.4.5	Co-production of healthcare services	23
2.4.6	Co-production into action.....	25
2.5	The challenge of coordination between different actors	25
2.5.1	Common Pool Resources (CPR).....	26
2.6	Social Media (SM).....	27
2.6.1	Social media categories	27
2.6.2	Social media for health and care	32
2.6.3	Benefits of social media for health.....	34
2.6.4	Usage of social media by older adults.....	44
Chapter 3 -	Methodology.....	50
3.1	Introduction	50
3.2	Research aim.....	50
3.3	Research objective.....	51
3.4	Research questions	51
3.5	Methodological choice: multimethod qualitative research.....	52
3.6	Theoretical framework	53
3.6.1	The range of theories.....	54
3.6.2	The selection of NPT.....	55
3.6.3	Use of Normalisation Process Theory (NPT) in this research	56
3.7	Data collection and sampling	60
3.7.1	Interviews	61
3.7.2	Online Document Analysis	63
3.7.3	Secondary data	64
3.8	Data analysis.....	65
3.9	Research governance and ethics	66
3.10	Quality in qualitative research	66
Chapter 4-	The Opportunities and Challenges of General (Existing) Social Media for Health and Care Co-production	68
4.1	Introduction	68

4.2	Objective	68
4.3	Chapter methodology	69
4.3.1	Data sources	69
4.4	Findings	70
4.4.1	Professional carers	71
4.4.2	Charity and voluntary organisations	73
4.4.3	Carers (informal carers)	79
4.5	Discussion	82
4.6	Conclusion.....	85
Chapter 5 - How Can Social Media Lead to Co-production (Co-Delivery) of New Services for Elderly Population?.....		87
5.1	Introduction	87
5.2	Chapter methodology	88
5.2.1	Data sources	88
5.3	Results	89
5.3.1	Social media enables equality through sharing experience of users as valued assets.....	89
5.3.2	Social media enables diversity by being inclusive of under-represented groups as well as by connecting diverse groups of people	92
5.3.3	Social media makes groups' experience accessible.....	95
5.3.4	Social media encourages reciprocity in sharing of knowledge and emotional support.....	98
5.4	Discussion	100
5.4.1	Summary of findings.....	100
5.4.2	Interpreting findings in the context of the wider literature	102
5.5	Conclusion.....	104
Chapter 6 - Developing New Social Media for Health and Care Co-production		106
6.1	Introduction	106
6.2	Objectives	106

6.3	The methodology used in this chapter	107
6.3.1	Material and methodology	107
6.3.2	Data sources	107
6.4	Investigation on new social media / applications	110
6.4.1	DALLAS programme.....	110
6.4.2	Selection of online web services (new social media).....	123
6.5	Co-production through new social media: needs and challenges.....	130
6.5.1	The health system needs to undergo change	131
6.5.2	Challenges in the use of New Social Media/applications for health and care purposes	138
6.6	Discussion.....	144
6.6.1	Summary of finding	144
6.6.2	Compare findings to the literature.....	148
6.6.3	Health and care service co-production through SM.....	150
6.7	Conclusion.....	152
Chapter 7 - Application Framework – Carer Board System.....		155
7.1	Introduction	155
7.2	Description of need scenarios.....	155
7.2.1	Scenario one - Human contact	156
7.2.2	Scenario two - Patient information sharing.....	156
7.2.3	Scenario three - Identifying needs and meeting them	157
7.2.4	Scenario four - Making the environment sustainable.....	158
7.2.5	Scenario five - The need for sharing of skills and experiences.....	158
7.2.6	Scenario six - Access to relevant information.....	159
7.2.7	Scenario seven - The need for respite support	159
7.3	The underlying challenges and potential resolution mechanisms	160
7.4	Mechanisms in response to the challenges	161
7.4.1	Circle of care	162

7.4.2	Templating	162
7.4.3	Time-banking	162
7.4.4	Resource recognition.....	163
7.4.5	Matchmaking (for human contact needs).....	163
7.4.6	Patient care record.....	164
7.5	SM for health and care	165
7.6	Trello	166
7.6.1	Trello in relation to supporting elderly health and care co-production...	167
7.6.2	Trello as a response to the challenges	168
7.7	Solutions	168
7.7.1	Solution I - Independent living	169
7.7.2	Solution II - Full-time carer	172
7.7.3	Extensions of Trello	173
7.8	Business model.....	175
7.9	New challenges and conflicts caused by introduction of Trello	175
7.9.1	Technological dimension	176
7.9.2	Social/human dimension	176
7.9.3	Organisational dimension.....	176
7.9.4	Macro-environmental dimension	177
7.10	Conclusion.....	177
Chapter 8 - Conclusion		179
8.1	Overview	179
8.2	Outline of the thesis.....	179
8.3	Theoretical contributions.....	186
8.3.1	CPR and co-production in health and care.....	187
8.3.2	Studies of social media.....	190
8.4	The implications for policy and practice	194

8.4.1	The sustainability of innovations	194
8.4.2	Combining top-down and bottom-up approaches	195
8.4.3	Re-purposing innovations	195
8.4.4	Measuring effectiveness of innovations	196
8.4.5	Organisational readiness	196
8.4.6	Balancing visions	196
8.4.7	Managing professional resistance and the reconfiguration of roles ...	197
8.5	Research strength and limitation	197
8.6	Recommendation for future work.....	199
8.7	Conclusion	200
Bibliography		202
Appendix 1 - The context of age		222
	The aging population.....	222
	Demography of health – the age pyramid	224
	Healthy life expectation	229
Appendix 2 - Template of forms		233
Appendix 3 - Social Media and Self-Management Report.....		236

List of tables

Table 2-1 – The number of carers in the UK, 2015	17
Table 2-2- Uses of social media for health communication users (Source: Moorhead et al. (2013)).....	36
Table 2-3 - Limitation of SM for health communication users (Source: Moorhead et al. (2013)).....	41
Table 3-1- Health and care with social media.....	52
Table 3-2- Representation of the four constituent NPT constructs (Source: May and Finch (2009)).....	57
Table 3-3 - NPT coding framework used for qualitative data collection (part 2).....	59
Table 3-4 - Overview of Data Collection.....	60
Table 3-5- Detail of interviewees.....	62
Table 3-6 - Secondary data - the topic guide	64
Table 3-7- Summary of secondary data	65
Table 4-1 - Social media and health and care	68
Table 4-2- Summary of primary data collection for Chapter 4.....	70
Table 4-3 List of participants from secondary data source used in chapter 4.....	70
Table 5-1- Social media and health and care	87
Table 5-2 - Summary of primary data sources for Chapter 5	88
Table 5-3 - Summary of secondary data sources for Chapter 5.....	89
Table 5-4- Social media for co-production	102
Table 6-1- Social media and health and care	106
Table 6-2 - Summary of interview data collection source for Chapter 6.....	107
Table 6-3 - Overall of applications investigated in Chapter 6	109
Table 6-4- Overview of DALLAS Programme	111
Table 6-5- Specifics of new health and care applications.....	124
Table 6-6- New applications and social media for health and care	147
Table 7-1- Summary of all scenarios	165
Table 7-2- Mechanisms.....	166
Table 7-3 - Solutions.....	174
Table 8-1- New health and care applications and programmes	183

Table A1-2 – The UK Population (thousands) (Source: Adapted from ONS 2010 – based population projections)..... 223

Table A1-3 - Scotland’s population (thousands) (Source: adapted from ONS 2010 – based population projections)..... 228

List of figures

Figure 2-1- Aging problems triangle (Source: Author's own, 2015).....	10
Figure 2-2-Yearly mean cost (€). females: continuous line; male: dotted line.....	10
Figure 2-3- Multiple exclusion of elderly	11
Figure 2-4- Overview of health and social care structures in the health and social care (Source: Act, 2012)	15
Figure 2-5- Care providers – (Source: Richards (1999))	16
Figure 2-6 - The governance international co-production star (source: Bovaird and Loeffler (2013)).....	22
Figure 2-7 – The roles of users and professionals in the design and delivery of service	23
Figure 2-8- Coordination between different actors (author's own, 2014)	26
Figure 2-9- Social media groups (author's own, 2014)	28
Figure 2-10 SM usage among seniors (age 65+) between the 2006 - 2016.....	45
Figure 2-11 – Social media sites use by age group.....	45
Figure 2-12 - US Social networking user.....	46
Figure 3-1- Conflict and issues surrounding health and care system, redesigned by co-production (Author's own, 2017).....	50
Figure 4-1- Use Facebook to invite people to an event	75
Figure 4-2- Use Twitter to invite people to an event	75
Figure 6-1- Screenshot of a Better plan website	112
Figure 6-2- Good Neighbours' website screenshot	114
Figure 6-3 – No Delay's website screenshot	117
Figure 6-4- e-Redbook's' website screenshot.....	118
Figure 6-5- First step goal of Living it Up project.....	119
Figure 6-6- Living it Up portal.....	120
Figure 6-7- Living it Up partners	121
Figure 6-8- OurBigBox's screenshot.....	125
Figure 6-9- Inside of OurBigBox	126
Figure 6-10- Healthunlocked's screenshot	127
Figure 6-11- Babylonhealth screenshot	128
Figure 6-12- Jointly screenshot.....	130

Figure 6-13 - Health and care actors (Author’s own 2017)	131
Figure 6-14- Health and care actors (Author’s own 2017)	138
Figure 6-15- Conceptual model of healthcare service co-production (Source: Batalden et al. (2015))	151
Figure 7-1- The initial idea of Trello	167
Figure 7-2- Screenshot of Trello	168
Figure 8-1 - Specification of social media	193
Figure A1-1- Children and young people aged under 20 and older person aged 65+ as a percentage of the global population – (Source: World Population Prospects).....	222
Figure A2-2- Age pyramid - the UK 1985	225
Figure A2-3 - Age Pyramid - the UK 2010.....	225
Figure A2-4 – Age and employment pyramid – The UK compared to 2013 – (Source: Schwab, 2013).....	226
Figure A2-5- Age pyramid - the UK 2035	227
Figure A2-6 - Age pyramid - Scotland 2035.....	228
Figure A2-7- Estimated and projected population aged 70+ in Scotland, mid-2012, 2022 and mid-2037.....	229
Figure A2-8 - The projected percentage change in Scotland’s population by age group. 2012-2037 (Source: National-Statistics (2013b))	229
Figure A2-9- life expectation and healthy and unhealthy expectation in each part of Glasgow - (Source: SoctPHO,2013)	230
Figure A2-10- Male life expectancy and healthy life expectancy in Scotland	231
Figure A2-11- Females life expectancy and healthy life expectancy in Scotland ..	231
Figure A2-12- Life expectancy and healthy life expectancy in the UK – (Source: Office for National Statistics)	232

Chapter 1 - Introduction

Academics and policymakers recognise the importance of co-production for achieving better quality health and social care outcomes for the elderly population. Social media (SM) potentially represents an important tool in enabling co-production¹ by improving coordination and communication between patients, their carers, and the professional health and care system. However, despite the importance of the role of SM in co-production, there are as yet very limited studies that identify the potentials and pitfalls of SM as an enabler of co-production. In this thesis, I aim to explore the current and future uses of SM in better delivery and reshaping of health and social care services.

1.1 Context

Health in the EU faces the three challenges of ageing, fiscal restriction and social inclusion (Carretero et al., 2012). In the United Kingdom (UK) the number of elderly people will increase to 6.6 million over the next 25 years. In Scotland, by 2035, the 74+ years group is projected to have grown by 82%. It is the most elderly age-groups of the population that are projected to increase most dramatically.

Though life expectancy has increased in recent times, this has not been accompanied by an increase in the expectation of healthy life. Life Expectancy (LE) refers to the estimated average lifespan of a person. LE only captures expected lifespan and not Healthy Life Expectancy (HLE). HLE refers to the expected 'healthy' lifespan of a person. It is derived from the LE and self-reported state of health captured by a survey of both mental and physical health. This estimate is used to show trends in the health of populations, facilitate allocation of resources and planning of services, and evaluate health outcomes (ScotPHO, 2013). Data shows that people can expect a considerable period of unhealthy life in some regions of Scotland as each individual is expected to live an average of 16.67% of their life with some health impairment. The figures on

¹ "Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours." BOYLE, D. & HARRIS, M. 2009. *The challenge of co-production*. London, New Economics Foundation.

unhealthy LE are higher in areas with lower socio-economic status. However, as indicated by research on Greater Glasgow and the Clyde Areas with longest life expectancy (which are usually those with the highest number of elderly) tend to have the shortest period of living unhealthily.

As a consequence of the matters described above, this study focuses on three important types of problems caused by the aging population in Scotland, and the wider UK. These problems can be described as follows: 1) the population of older people is increasing; 2) their escalating health needs will increase demands on health services in ways that will exceed allocation of resources; 3) older people and particular cohorts with acute needs face barriers (social exclusion) that impair their ability to take advantage of services. These issues will lead to gaps such as an increasing gap between the demand for services and the available resources. In other words, there is a need for the government to provide increasing expenditure for delivery of health and social care services. At the same time, the needs of the elderly person for services has increased in a period in which their personal income has often fallen. Moreover, older people are regularly excluded from society due to a number of reasons, such as reduced communication with society, inadequate access to services, absence of engagement in public activities, and loss of close family or friends. These forms of exclusion for some people persist from earlier in life whereas for others this is only experienced as they become older (Social-Exclusion-Unit, 2005). Another cause of exclusion is the lack or reduced productivity that leads to older people being marginalised by society.

The statistics show that the needs of elderly people are growing and there is an increased requirement for carers (Carretero et al., 2012). Currently the population of informal carers is more than 10% of the 65M population of the UK. It is projected that this number will increase to nine million of 73.2M (around 12% of population) in the next 25 years. The current value of care is worth an estimated £132bn per year, approximately equal to the total annual cost of health spending in the UK, which was £134.1bn in year 2014-15 (Buckner and Yeandle, 2015). So, an important challenge relates to the question of how to allocate resources for the care and health of elderly people in the future. Depending solely on economic growth to fulfil the finance needs of public services is unlikely to meet these needs in a time of austerity and will inevitably lead to poorer quality of service and outcomes. Hence, new ways of meeting

the needs for health and care are essential (Boyle and Harris, 2009). In this respect, there is a large pool of informal carers who need to be managed to achieve care needs. In other words, we need to consider how to utilise diverse resources.

Currently, family and neighbours are not properly coordinated to provide care services to the elderly population. In the current context, it is unlikely that economic growth will be sufficient to meet growing demands for health and social care services. Hence new ways of overcoming this shortage are needed (Boyle and Harris, 2009). In order to reshape service delivery, we need to equip services with different resources. The Health and Care system in the UK and Scotland is being reformed. The Scottish government has announced the need for better coordination and integration in this process (Christie, 2011). There are attempts to find new methods of providing public services. Examining the concept of co-production is an initial step in reforming service delivery. Boyle and Harris (2009) give a definition of co-production:

“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are coproduced in this way, both services and neighbourhoods become far more effective agents of change.”(Boyle and Harris, 2009)

There are a range of perspectives on the production and use of health and care services. A critical aspect of such services is the governance of their production and use. In this context, one strong standpoint sees health and care resources as ‘common pool resources’ (Ostrom, 1990). Common Pool Resources (CPR) refer to Ostrom’s point as:

“[A] system that is sufficiently large as to make it costly (but not impossible) to exclude potential beneficiaries from obtaining benefits from its use. To understand the processes of organising and governing CPR, it is essential to distinguish between the resource system and the flow of resource units produced by the system, while still recognising the dependence of the one on the other.” (Ostrom, 1990)

This common pool of resources may involve patients, informal carers, social carers, volunteers, professional carers (caregivers), and health professionals who can be seen as coproducers of health and care services. In this research, I focus on informal carers, volunteers and patients, and examine how this large pool of informal carers and patients could, with more careful utilisation (through SM), further augment the effort devoted to care in the UK. Current public services are poorly equipped to exploit the potential social economy of family and neighbours. Co-production offers ways to manage informal care resources. The full participation of informal carers in the co-production of health and care has the potential to play a significant role in the sustainability of health and care delivery. The broad categories of services are identified as co-production (Bovaird and Loeffler, 2013) 1) co-commissioning; 2) co-design; 3) co-delivery; and 4) co-assessment.

A pressing issue is the question of how to coordinate these massive resources with the formal health and care system to enable true co-production of health and care. Increasingly, e-health is seen as the tool to re-shape healthcare systems (Gaddi et al., 2014). SM is seen as a critical enabler for co-production (Lin and Lu, 2011). Communications is a key element in co-production that enables coordination across various boundaries. SM can help in this regard as it cuts across boundaries and is well understood.

SM constitutes a set of online tools for the creation and sharing of digital content. SM aims for widespread use and is capable of supporting an unlimited number of users. Kaplan and Haenlein (2010) defined SM as “a group of internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user generated content”. Dissemination of content operates at internet speeds. It has been argued that SM has caused a change in social action in many areas (Asur and Huberman, 2010, Househ et al., 2014). SM increases social interaction between patients and health organisations. Moorhead et al. (2013) explain that SM is a powerful tool for collaboration between users and it acts as a social interaction mechanism for its wide range of professional and non-professional users. It empowers the public and patients by enabling them to communicate with each other and exchange health information (Asur and Huberman, 2010, Househ et al., 2014, Kurahashi et al., 2016). It also enables users to discuss sensitive issues (Colineau

and Paris, 2010, Kim et al., 2014). Moorhead et al. (2013) conducted a systematic review of uses of SM for health and showed that SM offers peer, social, and emotional support for its users. They also demonstrate that SM increases interactions for patients, and their families and friends.

The term of SM was coined by Shipley after his study and reports on technology trends (Newson et al., 2009). SM has since become media for the creation and maintenance of connections and interactions amongst individuals (Kwai Fun IP and Wagner, 2008, Frisch et al., 2014). Social Media sites have grown to be among the most often visited sites worldwide. (Alexa.com, 2017).

Several studies (Kaplan and Haenlein, 2010, Daneshvar, 2011, Hall et al., 2008) categorise SM into nine groups: (1) wikis; (2) blogging; (3) micro-blogging; (4) content communities; (5) forum; (6) instant messaging; (7) social network sites (SNS); (8) mobile SM; and (9) virtual world and online social gaming. I consider all of these nine groups as falling within SM.

In health and care, I further divide SM into three groups: A) SM that is created for general purpose use and is now used for health and care e.g. Facebook Groups (FBG); B) the applications that are created for health purposes and that make use of generic SM for other purposes (e.g. 3D Doctor or some other health applications that make use of Skype to connect patients to their doctors); and C) the SM applications created for health and care purposes that use the concept of SM (Health SM) e.g. healthunlocked.com is new SM for health purposes (Daneshvar and Anderson, 2014).

1.2 Research aims and questions

The coordination of carers with the formal health and social care system can lead to better management of resources which in turn results in the improvement of the quality of life for the older population. Therefore, I investigate the current and possible future for SM as an enabler of co-production in health and care. To achieve this goal, two main sets of questions are asked: 1) what are the current uses of SM in health and social care? 2) how can SM be reshaped to enable (and reshape) health and care co-production?

I consider a typology of opportunities and restrictions of SM for health and care. Existing health and care services bundles with (1) existing or (2) new SM tools. New health and care services bundles with (3) existing or (4) emerging SM tools.

As a result, in this study, four main sets of questions are raised and are addressed in the empirical chapters.

1. How does current SM support co-delivery of current health and care services? (Chapter 4)
2. How can current SM lead to co-delivery of new services? (Chapter 5)
3. How can SM be reshaped to make co-delivery of services possible? (Chapter 6)
4. How can SM be reshaped to make possible co-delivery of new services and improve integration of health and care services? (Chapter 6)

In answering these questions, I will explain the benefits as well as the challenges in relation to the use of SM as an enabler of co-production in health and care. This will also explain how the notion of CPR can be used for the management of health and care resources.

1.3 Outline of the dissertation

This section provides an overview of my research, which investigates the applications (general and special SM) that facilitate health and care co-production. Qualitative methods have been chosen for this research. This research focuses on multiple areas of literature in e-health including Health Informatics, Social Scientifics Studies, and Information Systems (Socio-technical systems).

Chapter 2 - Literature review – I review the literature that informs my multidisciplinary perspective in the study of health and care. In order to execute this, I start by explaining the literature in health and care and some of the problems faced by the elderly population, and some predictions for the next 25 years. I also highlight the potential of informal carers in responding to the associated problems. The concluding issue is the question of how to coordinate this massive resource (informal carers) with the formal health and care system to enable true co-production of health

and care. The literature review also shows that e-health is increasingly seen as the tool for re-shaping the health and care system. In particular, SM is seen as a critical enabler for co-production. In this review, I highlight how SM can act as a key in service redesign and for the adoption of co-production. This chapter concludes by exploring the problems in current uses of existing SM for the health and care of the elderly population.

Chapter 3 - Methodology – Having problematised the gaps in health and care in Chapter 2, in Chapter 3 I go on to explain the frameworks used for introducing the objectives of the research and all of the research questions. I develop a map which shows how SM may face health and care systems. Two main sets of questions are asked and a typology of opportunities and limitations of SM for health and care are presented.

I design a qualitative study, which investigates the sociotechnical aspects of the current and possible future uses of SM by different organisations and groups of health and social care as an enabler of co-production in the UK. My appraisal adopts a socio-technical technique (May and Finch, 2009), using a mixed methods framework, including multiple methods. I use Normalisation Process Theory (NPT) as my theoretical framework to design this study. I then use a range of qualitative data collection methods to conduct the research. I conduct 18 semi-structured interviews which focus on the services offered, the types of online applications (particularly SM) used, their challenges and the future possibilities of SM. I also observe and analyse the activities and contents of online groups to collect data. Combining different methods enabled me to triangulate the data sources to validate my findings. I then use thematic analysis, and draw on principles of co-production (equality, diversity, accessibility, and reciprocity) as a deductive coding framework to analyse my findings.

Chapter 4 – How existing SM helps the health and care system – This chapter finds the uses of SM in health and care organisations as a tool for co-production and explores the benefits and issues around this matter. In this chapter, the focus is on the organisations that supply professional care services, voluntary and charity organisations working in health and care services and with individual patients, and carers who use SM. I study the use of SM in coordination and communication across

boundaries and the engagement of carers, patients and organisation and their benefits, limitations, challenges and opportunities.

Chapter 5 - How can SM lead to co-production (co-delivery) of new services? – This chapter investigates how SM helps health and care organisation and informal carers to develop new health and care services. To do this, I use a framework to conduct an investigation into how SM is used for new health and care services to facilitate co-production between different actors. I explore how SM can enable the four principles of co-production by offering equality, diversity, reciprocity and accessibility. In this section, I evaluate the opportunities, challenges and issues associated with using SM.

Chapter 6 - How can newly developed applications (SM) facilitate health and care services (cater for existing needs or the formulation of new services)? – This chapter explores the benefits, issues and gaps of the new applications or SM (not general SM application) developed for health and care services and explores how they enable co-production. In this chapter, I present different SM and online activity of some SM applications developed for health and care purposes. The Chapter studies various developments in the government-funded DALLAS project, and a number of other applications. The chapter discusses some of the reasons for termination or change of the developments.

Chapter 7 – Software design (framework for a new SM) – In this chapter, I review different health and care scenarios as identified through the interviews and show how existing applications can cater for various needs of the elderly population and their carers. In order to do this, I suggest repurposing and customising an existing application that uses concepts from SM.

Chapter 8 – Discussion and conclusion– In Chapter 8, I bring together the findings of Chapters 5, 6, and 7 and link them back to the typology of opportunities and restrictions of SM for health and care. Through this I contribute to knowledge, practice and policy.

Chapter 2 - Literature Review

2.1 Introduction

The internet plays a vital role in the daily lives of people to the extent that some argue that access to the Internet is a human right (Wicker and Santoso, 2013). Communication and information management has been increasingly affected by the internet. Medicine and health and care have been particularly highly influenced by the Internet in the last few years. For instance, a study shows that 80% of internet users have looked specifically for information about health topics (Fox, 2011b). Gaddi et al. (2014) argue that this will play a very important role in changing and shaping healthcare systems in the twenty-first century.

This chapter provides a review of the literature of applications of SM in the health and care sector with a focus on co-production. To achieve this aim, I review the relevant literature in five different areas:

- 1- An overview of the problem: aging population and their needs;
- 2- The history of information and communication technology in health;
- 3- The definitions to be used throughout this study;
- 4- An overview of co-production in healthcare;
- 5- What SM is and what its uses are in co-production of health and care.

2.1 Aging population

The Encyclopaedia of Population sets the definition for *older people* as “the aging of population often is measured by increases in the percentage of people in the retirement ages. The definition of retirement ages varies, but a typical lower cut off number is 65 years. A society is considered relatively old when the proportion of the population aged 65 and over exceeds 8 to 10 percent” (Demeny et al., 2003). This is the age by which most people will be retired (albeit there are plans to increase the retirement age by 2 years (Batchelor, 2017)). I therefore define elderly people (also referred to as (the) older population/people or aged population/people in this thesis) as those who are living through their retired period of life.

The population of elderly people is rapidly increasing. In particular, the number of elderly people in the UK is predicted to increase to 6.6 million over the next 25 years. By 2035, Scotland will also see a significant rise in the 65+ years olds (85% increase) (National-Statistics, 2013a). This has led to insufficient resources to meet the health and care needs of the elderly population, as well as the social exclusion of the elderly population (Carretero et al., 2012). This is referred to as the aging problem triangle (Figure 2-1).



Figure 2-1- Aging problems triangle
(Source: Author's own, 2015)

The age of retirement in the UK is 68 (Clemens and Parvani, 2017) and, as Alemayehu and Warner (2004) state, almost 60% of the total cost of health and care in a lifetime is spent on addressing issues arising after this age. Figure 2-2 by Carreras et al. (2013) shows a yearly mean cost from birth to death. As can be seen in this figure, the greatest change of health and care in one's life occurs after the age of 50, and after 65, the cost of living goes up sharply. This cost in turn has led to an increasing gap between real income and the cost of meeting living demands.

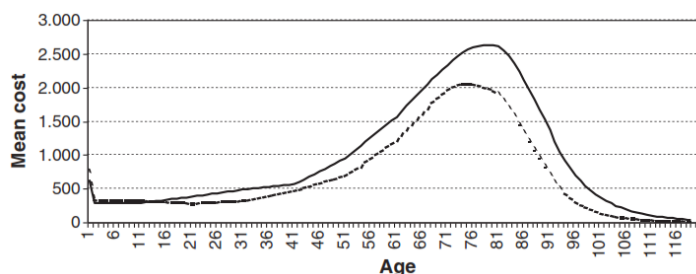


Figure 2-2-Yearly mean cost (€). females: continuous line; male: dotted line

Moreover, older people are regularly excluded from society because many older people have very limited resources. Other issues, such as reduced communication with society, inadequate access to services, absence of engagement in public activities, and loss of close family or friends are also amongst the factors leading to exclusion. These forms of exclusion for some people persist from earlier in life, whereas, for others, this is only experienced as they become older (Social-Exclusion-Unit, 2005). Another cause of exclusion is the lack or reduced productivity that leads to older people being marginalised by society. The Social Exclusion Unit (2005) is concerned with some of the issues that cause exclusion, particularly for those of pension age and the very old.

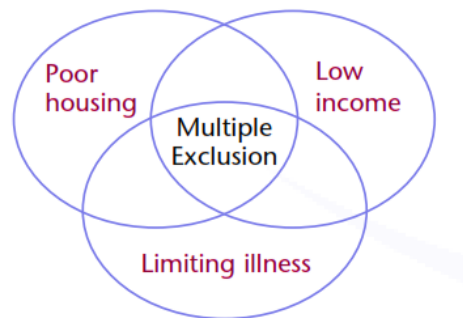


Figure 2-3- Multiple exclusion of elderly

These issues will dramatically affect the need for government expenditure to provide and deliver health and care services whilst the income of this population remains static or falling and they become increasingly excluded from society. An important challenge, therefore, relates to the question of how to reshape the delivery of health and care and make better use of resources for elderly people in the future. Depending solely on economic growth to fulfil the financial needs of public services is unlikely to meet the needs in a time of austerity and will inevitably lead to poorer quality of service and outcomes. Hence, new ways of meeting the needs for health and care are needed (Boyle and Harris, 2009). The issue of the aging population is discussed in more detail in Appendix 1.

2.2 A brief history of Information and Communication Technology (ICT) use in health and care

From 1950 until now, ICT has affected different aspects of the health and care sector. ICT has influenced the ability of people to access health service. Marinkovich et al. 1996 (cited by Milenković et al. (2012)) state that healthcare has used computer technology since 1960, with this developing over time through various stages. The first documented case of the use of ICT technology in the health system is a 1965 project between Lockheed and EI Camino Hospital in California. They combined medical equipment and a computer to develop computerised tomography as a new diagnostic tool. This led to the first clinically-oriented Hospital Computer Information Systems (HCISs) called the Technicon Medical Information System (TMIS). In the seventies, hospital automation was focused on centralised, integrated, closed systems that relied on large central (mainframe) computers. In the 80s, the concept of information systems in medicine was developed in differential diagnoses and methods of information synthesis. In the nineties, process integration was an important theme. Integrating the health information system, forming an integrated database of medical and administrative data or knowledge, and communication. The goal was an all-embracing healthcare system including communication and interaction with other systems aimed at supporting doctors rather than patients. This went on well into the 2000s, during which time clinical systems were oriented to professional workflow and did not look to provide a high-quality patient experience.

The aim of providing better health services for patients was intended to integrate information and communication technologies in health care in Europe. This was done through offering ways to improve the mobility of people and giving the opportunity to take control over the entire health care system's economy and quality, with the aim of managing large health systems. In this manner, different countries have used various approaches to offer better health through use of ICT to both citizens and health professionals.

The aim of providing better health services for patients led to initiatives to integrate information and communication technologies in health care in Europe, the sub-aims being to provide better health service for patients through offering ways to improve

the mobility of people and giving them the opportunity to take control over the entire healthcare system's economy and quality, and managing large health systems. Milenković et al. (2012) shows, however, that there is no ordinary approach followed by EU countries. The approaches depend on socio-economic situations leading to finding out how to address problems of management and control of the health system in their countries. He argued that, in the EU, there are huge differences in the use of ICT for healthcare. The statistics recently published by EU show that, in 2018, in the Netherlands (given the rate of internet access in EU), 71% of patients sought health information online. This figure is 20% higher than the EU average (51%). The average number of EU countries that use prescriptions over the Internet is 6%, with such practices being adopted only in three countries. In Denmark, 97% of doctors issue online prescriptions, with the numbers for Sweden and the Netherlands falling at 81% and 71% respectively. Telemedicine, which allows doctors to have remote access and control of disease development with their patients, or the ability to monitor chronic diseases, is still very new to different countries. These services are only rarely offered to patients e.g. only 9% of physicians in Sweden and 3% of those of the Netherlands and Iceland. The average use of the Internet for health purposes has increased from 34% (in 2010) to 51% in 2018 (Eurostat, 2018).

Milenković et al. (2012) argued that there was still some confusion in electronic healthcare systems in the EU. On the other hand, a large number of doctors agree that ICT increases the quality of offered services. However, the main reason for not using ICT by doctors is regarded as being related to shortage of training and technical support. Furthermore, Rinaldi (2014) argues that patients claim that they have higher engagement in their own care process by being able to generate content and having higher accessibility to information. He further adds that doctors also see this as a positive patient empowerment. In this manner, I observe that there are numerous but non-uniform approaches used by different countries in offering better healthcare through the use of ICT to both citizens and health professionals.

2.3 Defining health, care and ICT for health and care

Before I go further into the details of applications of SM in health and care sector, in this section I define some foundation terms used throughout this study.

2.3.1 What is care

The definition of *care* in the Oxford English Dictionary is given as “the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something”. The World Health Organisation (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Sepúlveda et al., 2002). This includes providing relief from pain, integrating the psychological aspects of patient care, supporting an active life, helping the family cope with patient illness, and enhancing quality of life.

There is also a more focused concept, home care, which pertains to supporting a person with special needs to stay in their home. This includes in particular those who are getting older, are chronically ill, recovering from surgery, or disabled. Such home care services comprise personal care and health aid at home (Sepúlveda et al., 2002).

In the health sector, there are two widely used organisational categories of care: Social Care and Health Care. Figure 2-4 **Error! Reference source not found.** provides an overview of health and social care structures in the Health and Social Care on base Act 2012.

Finally, in terms of social care, the UK government has not established any clear concept from Low’s Commission for Adult Social Care (Dorrell, 2012), but it gives a definition as follows: “Adult social care means the care and support provided by local social services authorities pursuant to their responsibilities towards adults who need extra support. This includes older people, people with learning disabilities, physically disabled people, people with mental health problems, drug and alcohol misusers and carers. Adult social care services include the provision by local authorities and others of traditional services such as care homes, day centres, equipment and adaptations, meals and home care. It can also extend to a range of so-called non-traditional services – such as gym membership, art therapy, life coaching, personal assistants, emotional support, and classes or courses. Adult social care also includes services that are

provided to carers – such as help with travel expenses, respite care, and career advice. Finally, adult social care also includes the mechanisms for delivering services, such as assessment, personal budgets and direct payments” (Parliament, 2013). It is also worth mentioning that the governance structures of health and care in the four countries within the UK have some differences and, therefore, investments vary between the countries (Doheny, 2015).

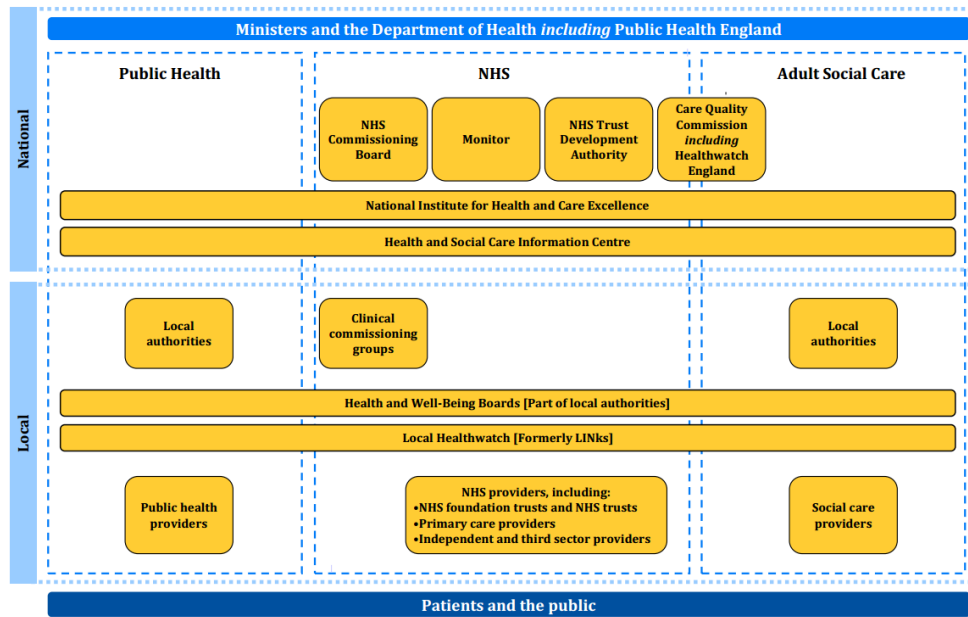


Figure 2-4- Overview of health and social care structures in the health and social care (Source: Act, 2012)

2.3.2 What is social care?

Social care has been defined in various ways. The Department of Health and Social Care (DH) defines *social care* as follows: “[S]ome people need extra care or support - practical or emotional - to lead an active life and do the everyday things that many of us take for granted. The government is working to provide a social care system that provides care for those who need it, and which enables people to retain their independence and dignity.” (Willcocks and Sykes, 2000)

Social care is provided by local authorities and the private sector to elderly people. It is offered in personal homes, care homes or day centres (BBC, 2008). It is intended to describe help and support for people in order to enable them to have independence in life (ageUK, 2013).

2.3.3 Who is the carer

The *carer* is referred to as “a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person” (Oxford English Dictionary). The term *carer* refers both to paid practitioners and family/friends who have caring roles. The latter group is also known as informal carers. Figure 2-5, presents a grouping of carers:



Figure 2-5- Care providers –
(Source: Richards (1999))

Cares can be divided into two main groups: care workers and carers (informal carers).

The term *care worker* (or *formal carer*, *professional carer*, *paid practitioner carer* or *caregiver*) is used to refer to someone who is employed to provide care for other people. This is what is referred to as formal care in the previous paragraph. They are paid professional care workers, for example, some care workers who are employed in residential homes, day nurseries, hospital, and clients’ homes. This group of carers deliver professional care and are employed to take care of and support people in need of care in formal settings. They are usually registered in some organisation that provide care, like the general nurse, health visitor, healthcare assistances and district nurses (Richards, 1999).

The term *carer* (informal carer) refers to someone who provides care on an informal, voluntary and unpaid basis. They frequently take on considerable responsibilities when delivering care for others. In order to do this, they may or may not get support and help

from a care worker. They can be family members or voluntary care givers from charities or voluntary organisations like the Women’s Royal Voluntary Service. This group are family members, relatives, friends, volunteers, neighbours or someone non-professional and untrained who looks after an individual, mostly within the context of a person’s home. This type of carer does not undertake this as work or give this service for money. Informal carers offer care for supporting daily needs to providing regular visits at home for a chat. Carers UK, a national membership charity for carers that operate in the UK, provides the following definition “[c]arers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Most of those carers will look after an elderly relative, sick partner or disabled family member at some point in our lives. But whilst caring is part and parcel of life, without the right support, the personal costs of caring can be high”. I refer to this group as ‘informal carers’. This group is also regarded as family/friend carers (Carers&Confidentiality, 2013) who support health professionals in giving care.

2.3.4 Value of carers in the UK

The census the population of carers in the UK for 2015 show an increase in the number of carers since the last census in 2001, from 5.22 million, with this constituting an increase of 629,000 people who are providing care in only 10 years. Research has also suggested that this number is expected to rise by 40%. This research suggests that there is a 2.3 million increase in the number of adult carers and the carer population in the UK will reach nine million. This analysis showed that, at a certain stage, there will be 3 carers in every 5 people (Buckner and Yeandle, 2015).

Regions	Number of Carers
England	5,712,398
Scotland	509,796
Northern Ireland	220,501
Wales	384,056
UK total	6,826,751

Table 2-1 – The number of carers in the UK, 2015

The value of care offered by informal carers is worth an estimated £134.1bn per year (Buckner and Yeandle, 2015). There is therefore currently a high reliance on the willingness of carers to offer their services.

2.3.5 Health care

Health care is defined as the “prevention, treatment, and management of illness and the preservation of mental and physical well-being through the services offered by the medical and allied health professions”. The UK health care system offers its professional care services at three levels: primary care (e.g. General Practitioner (GP) services, nursing services and home caring), secondary care (e.g., hospital services like general local hospitals, physiotherapy services), and tertiary care (e.g. specialist cancer care, specialist hospitals).

Primary Care: Primary care offers the first stage of care and treatment to patients. It provides initial contact to a patient by means of a healthcare provider, usually a GP, dentist or optician. The nature of primary care offered by GPs has changed over the years. For instance, maternity services are now performed by district midwives or in hospitals. General practitioners now offer more help than previously. There are also many more group practices currently running in the country. They now use software applications to record and manage patient information.

Secondary Care: Secondary care is offered to patients in the hospital. Most people are referred to hospitals by their GPs or through accident and emergency departments or from a telephone and internet-based help system. Since 1991, hospitals have been managed by health care ‘trusts’, which provide hospital and mental health care services, ambulances and special services.

Tertiary Care refers to specialised hospital services.

2.3.6 Integration of health and social care

Care for older people is frequently fragmented between sectors despite the claim that it should be coordinated around their needs. To address this need, integrated care, where health and social care professionals work together in a coordinated way, is required (Scottish-Government, 2012). In May 2012, the Scottish government has

announced the approval of consultation to change the way that the NHS and Local Authorities work together. In this movement, there are plans to integrate health and care organisations with the aim of transforming adult health and social care services with the aim of creating a unified setting as seen by patients, service users and carers. This integration is also aimed to improve all adult health and social care services. England is also going through a similar plan with the act scheduled for 2018 (Department_of_Health, 2013).

To achieve this the Scottish Parliament has set a series of objectives. Firstly, health and social care should be integrated around the needs of the elderly, their carers and other family members. Secondly, the act is to be led by strong and consistent clinical and care professionals. Thirdly, health and care providers will be held jointly accountable for the improvement of the delivery of services. Finally, the provided services are to offer flexible, sustainable financial mechanisms for clients (Scottish-Government, 2012).

2.4 Co-production

Many services are produced and consumed simultaneously. Particularly in the course of a service being delivered, quality is shaped and offered at the time of service delivery at the point where consumers and producers meet. In other words, when receiving services, customers are constantly evaluating the service delivery process as well as evaluating the outcomes. For instance, while receiving call centre services or nursing services, the friendliness and responsiveness of the service provider is very important.

Currently, many public services are poorly equipped to use the potential social economy of family and neighbours. Depending solely on economic growth to fulfil the finance needs of public services could lead to a less efficient quality of service and less efficient outcomes. Hence, new ways of overcoming this shortage are required (Boyle and Harris, 2009). In order to reshape service delivery, we need to engage different resources. Examining the concept of co-production is an initial step in reforming service delivery.

Co-production suggests that service users must be made active in shaping their own services. Failure to involve users in the process is a waste of skills and reduces the ability to operate change (Boyle and Harris, 2009). So co-production criticises a lack of use of people's abilities as useful resources in the creation of services.

Neva Goodwin, an economist, refers to these resources as the 'core economy'. Failing to appreciate this core economy may lead to isolation, time poverty, low levels of trust, engagement and social infrastructure. Public service reform must therefore appreciate the core economy, discover its potentials, and support its growth (Boyle and Harris, 2009). Through co-production, there is possibility to rebuild and strengthen this core economy by formulating social networks (of service users, their families, friends and neighbours) such that demand on professionals is reduced (Boyle and Harris, 2009, Palumbo, 2016). This process involves shifting the power balance and responsibility from professionals to individuals and having them work beside one another (Boyle and Harris, 2009, Palumbo, 2016). Involving the user not only leads to improved services, but can also help in reducing costs. Research shows that changing demographics can lead to more co-production, due to older individuals having a higher tendency than younger individuals to contribute to public services (Löffler et al., 2008).

In general, the main motives for customers to get involved in public services are to improve the quality of public services by using a wider pool of expertise, to provide a wider variety of services, to make public services better fit users' needs, and to cut costs. Thus, in order to achieve real co-production, citizens and public sector should work together. Hence co-production is best defined as

“professionals and citizens making better use of each other's assets, resources and contributions to achieve better outcomes or improved efficiency”. (Bovaird and Loeffler, 2013)

2.4.1 The history of co-production

In the late 1970s, Elinor Ostrom coined the term *co-production*. She initially used this term to explain the reason why neighbourhood crime rates went up in Chicago when Chicago's police lost an essential source of insider information from citizens (Boyle and Harris, 2009). She explained that police as a public service had to use

unacknowledged knowledge which was held as an asset of its service users. So, in other words, the police needed the public as much as the public needed the services of the police.

The concept of ‘core economy’ (Neva Goodwin; Edgar S. Cahn), which refers to resources in people’s lives (including time, energy, wisdom, experience, knowledge, skills, etc.), can be used to explain co-production. Society and public services run on the core economy (Stephens et al., 2008). In the same way, users and professionals have an important role to play in developing services. Individuals, their families and friends, and social communities are important agents in the production of services they use. In this manner, professionals should engage with the core economy, support its growth, and try to enhance its reach and potential. They should use individuals’ skills and experiences to deliver public services by building ‘multi-faceted networks of mutual support’ (Stephens et al., 2008). It is therefore a challenge for professionals and policymakers to make the best use of public abilities in order to make good the shortcomings of the services.

2.4.2 Types of co-production

A broad category of services are identified as co-production (Bovaird and Loeffler, 2013):

- **Co-commissioning** of services, which includes co-planning of policy, co-prioritisation of services, and co-financing services (e.g. fundraising);
- **Co-design** of services, for instance designing of user forums, service design labs, customer journey mapping;
- **Co-delivery** of services, including co-managing services (e.g. leisure centre trusts, community management of public assets), and co-performing of services (e.g. peer support groups);
- **Co-assessment**, which embraces co-monitoring and co-evaluation of services.

These four are seen as the outer ring of co-production (Figure 2-6).

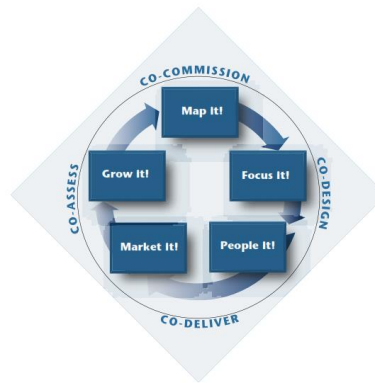


Figure 2-6 - The governance international co-production star
(source: Bovaird and Loeffler (2013))

2.4.3 Asset-based Approach

There is an approach called the ‘asset-based approach’, which aims to make known the skills of individuals, show them that they are valued, allow people to connect, and encourage them to co-operate. This has the potential to lead to community trust and cohesion, which can add value to existing public services. This approach brings together the knowledge and resources of individuals in order to create solutions to problems and enhance interaction amongst citizens (Needham, 2009, Chambers, 2011, Bovaird et al., 2015). In this process, co-production is an enabler of change in the relationship between individuals and communities that encourages collaboration. This increases the confidence of staff in sharing power with individuals (Needham, 2009). The asset-based approach is designed to improve the quality and longevity of life by promoting self-esteem and revealing the skills of individuals and communities.

2.4.4 Benefits and problems in co-production

Through co-production, people will be recognised as assets of society, and their work in looking after others and maintaining healthy communities has real value. In this approach, the reciprocal attitude of building trust and respect, and developing social networks with long relationships is promoted (Boyle and Harris, 2009).

Officials have noted some of the benefits of co-production and broadly define it as: “establishing a partnership between citizens and government to tackle a social problem”. They have taken some initiatives in co-producing public services such as co-design. However, many of these initiatives are short-term (Boyle and Harris, 2009).

It is also evident that co-production has the ability to reduce costs. For instance, research on nurse-family partnership programmes in the US reveals a reduction in child abuse and neglect, which means a saving of \$41,000 per child involved in public spending. Moreover, it can lessen the number of youths involved in matters that require to go to court. In Washington, this shows another \$11,510 saving of costs (Boyle and Harris, 2009). Other sources of cost reduction are encouraging self-help, supporting better use of scarce resources, growing social networks and improved well-being.

Despite the many potential benefits of co-production, it faces many challenges in the UK and elsewhere. The difficulties are both in terms of presenting appropriate measures of its benefits to people, and also in capturing the innovative resources of the population. This is because, savings and costs may incur at various places which makes it difficult to justify. Co-production is complex in planning and development.

		Responsibility for design of services		
		Professionals as sole service planner	Professionals and service users/ community as co-planners	No professional input into service planning
Responsibility for delivery of services	Professionals as sole service deliverers	Traditional professional service provision	Professional service provision but users/communities involved in planning and design	Professionals as sole service deliverers
	Professionals and users/communities as co-deliverers	User co-delivery of professionally designed services	Full co-production	User/community delivery of services with little formal/ professional
	Users/communities as sole deliverers	User/community delivery of professionally planned services	User/community delivery of co-planned or co-designed services	Self-organised community provision

Source: Adapted from Carnegie Trust (2006), 'Commission for Rural Community Development - Beyond Engagement and participation, user and community co-production of services.' By Tony Bovaird, Carnegie Trust.

Figure 2-7 – The roles of users and professionals in the design and delivery of service

2.4.5 Co-production of healthcare services

A growing number of scholars are addressing the importance of co-production in healthcare services. To enable co-production in healthcare, health professionals and

patients need to form partnerships in co-design, co-delivery, co-assessment and co-commissioning of services (Loeffler et al., 2013) In this way, Loeffler's co-production framework covers many aspect of health services, but there are still many complexities in its development. Other authors have also mentioned various approaches in enabling this partnership between patients and professionals. For instance, the need for shared decision-making (Braddock, 2010), patient engagement in health activities (Carman et al., 2013), and patient activation as a way to enhance health (Hibbard et al., 2004), relationship-centred care (Beach and Inui, 2006), self-care and self-management of health services (Taylor et al., 2014, Ewert and Evers, 2014), and the collaborative redesign of health systems by devoting attention to the experiences of patients, carers and clinician health professionals can also be seen as ways to materialise co-production. Whilst many benefits exist, the challenges of co-production of healthcare services have also been addressed in recent studies.

Batalden et al. (2015) categorises the challenges into five main areas:

a) Diversity among patients: A large number of patients do not contribute to healthcare co-production, which could be largely due to severe health conditions; b) Power and responsibility: equal sharing of power and accountability for outcomes is neither desirable or achievable for many patients and health professionals (Ewert and Evers, 2014), (e.g. surgical errors of clinicians versus unhealthy choices by patients); c) Allowing the pendulum to swing too far: there is a possibility that professional expertise may be ignored as too much information is made available to patients, which may not be necessarily helpful; d) Contextualising standardisation: co-production leads to the adaptation of many healthcare services, which challenges the standardisation of practices. This is because patients and carers take up various activities and perform them in many different ways; e) A resistant healthcare culture: the training and engagement of patients and health professionals is difficult. Many health professionals revert back to their old ways of offering care, which makes co-production of healthcare challenging.

Overall, there is a potential for conflict and disagreement, and this is legitimate because the needs and wants of patients and professionals tend to be different. Other authors also highlight many difficulties in the materialisation of co-production in

healthcare. For instance, Ewert and Evers (2014) highlight that co-production activities can serve the needs of patients and carers who can and are willing to become involved in the care process. This leaves out many who have fewer opportunities to be part of the process. Moreover, there is a tendency to focus on the co-delivery of ordinary healthcare services rather than on the involvement in co-planning and co-design (Ewert and Evers, 2014). This excludes patients and carers from the matter of proposing and making change.

2.4.6 Co-production into action

In order to put co-production into practice, Cahn (2000), suggests 4 principles: a) **Equality**: to acknowledge the public as assets with skills, knowledge and experience in an equal manner; b) **Diversity**: to value different work by different people and include them in activities; c) **Reciprocity**: building trust and mutual respect between people and making people responsible for contributing such that they give back to others; and d) **Accessibility**: building social capital and giving people the opportunity to participate in a way that gives rise to parity. Whilst these different aspects are needed, putting all of these into practice may lead to conflicts of interests.

For instance, encouraging diversity and including different people in an activity could cause less equality and reciprocity because people would be less likely to contribute equally. I analyse these matters in more detail in Chapter 5. I will show how ICT can overcome some of the conflicts in co-production and then present how new asymmetries may be produced.

2.5 The challenge of coordination between different actors

Coordination between health, social care and carers (informal carers) constitutes a significant gap in the health system in the UK (Taunt et al., 2014). The society of the Local Authority Chief Executives (Christie, 2011) states that one of the most important problems addressed in reforming Scotland's public service is the need to improve the coordination of these bodies. However, despite the reform in the integration of health and care, carers are not clearly accounted for. Another difficulty is shown in poor strategic coordination between public service organisations with a mixture of objectives, and separate budgets and processes of accountability. In this regard, they

highlight that one aim of the new system is to overcome the “fragmentation and complexity in the design of public services” by “improving coherence, collaboration and integrated service provision between agencies” (Christie, 2011, Filipe et al., 2017). In the next section, the structure of the National Health Service (NHS) is discussed.

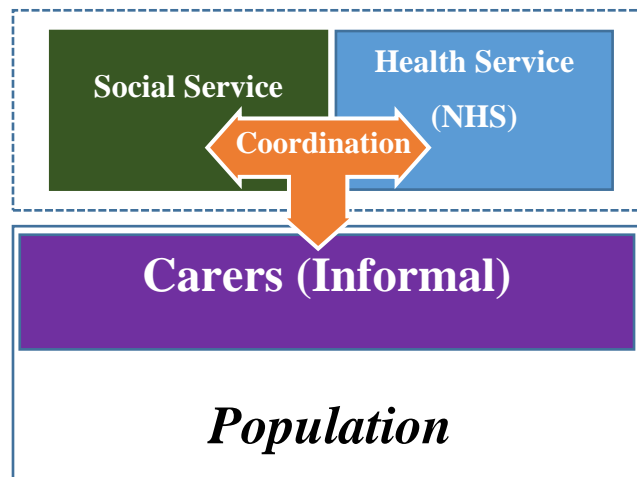


Figure 2-8- Coordination between different actors
(author's own, 2014)

2.5.1 Common Pool Resources (CPR)

There are a range of perspectives on the production and use of health and care services. A critical aspect of such services is the governance of their production and use. In this context, one strong standpoint sees health and care resources as ‘common pool resources’ (Ostrom, 1990). CPR refer to:

“[A] system that is sufficiently large as to make it costly (but not impossible) to exclude potential beneficiaries from obtaining benefits from its use. To understand the processes of organising and governing CPR, it is essential to distinguish between the resource system and the flow of resource units produced by the system, while still recognising the dependence of the one on the other.” (Ostrom, 1990)

The CPR requires polycentric governance, which involves semi-autonomous decision-making of different players by taking into account competitive and co-operative relationships and having conflict resolution mechanisms (Ostrom, 2010). This common pool of resources may involve patients, informal carers, social carers,

volunteers, professional carers (caregivers), and health professionals who can be seen as coproducers of health and care services. In this research, I focus on informal carers, volunteers and patients, and examine how this large pool of informal carers and patients could, with more careful utilisation, further augment the effort devoted to care in the UK. Current public services are poorly equipped to exploit the potential social economy of family and neighbours.

The full participation of informal carers in the co-production of health and care has the potential to play a significant role in the sustainability of health and care delivery. One pressing issue relates to the question of how to coordinate this massive resource with the formal health and care system to enable true co-production of health and care. This massive resource is spatially dislocated and temporally uncoordinated and engaged in responding to very local demands. Modern ICT is seen as a key enabler in overcoming such obstacles.

2.6 Social Media (SM)

SM are online tools for the creation and sharing of digital content. They are geared towards widespread use and are capable of supporting an unlimited number of users. Kaplan and Haenlein (2010) define SM as “a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content”. Dissemination of content operates at the speed of the Internet. It has been argued that SM have caused a change in social action in many areas (Asur and Huberman, 2010). The term was coined by Chris Shipley after his research and reports on technology trends (Newson et al., 2009). SM have since become media for the creation and maintenance of connection and interaction amongst individuals (Kwai Fun IP and Wagner, 2008). They are currently used widely by a diverse range of users and have grown to be among the largest number of most visited sites worldwide (Alexa.com, June, 2018).

2.6.1 Social media categories

Several studies (Kaplan and Haenlein, 2010, Daneshvar, 2011, Hall et al., 2008) categorise SM into nine different groups (**Error! Reference source not found.**).



*Figure 2-9- Social media groups
(author's own, 2014)*

2.6.1.1 Wiki

Wikis operated on web-based software that supports open editing by different users who can freely access the website and change its contents. In editing the website, participants expand the content without programming knowledge. The main idea is that people can freely contribute to adding new content and edit existing content and as a result collaborate in the expansion of the knowledge on the site. Cunningham (2008) describes Wiki designs as open, incremental, organic, mundane, universal, overt, unified, precise, tolerant, observable and convergent. They are usually managed through collaborative maintenance (Besten and Dalle, 2008). The most successful example of a wiki is Wikipedia, where individuals have collectively created an extensive source of reasonably reliable information.

2.6.1.2 Blogging

The term *blog*, coined by Peter Merholz, which is a clipping of the term *Weblog*, coined by John Barger (Newson et al., 2009), refers to a personal web diary. The meaning of *blog* has evolved over the past few years, as patterns of use and software have changed. It provides a publicly accessible personal journal of an individual (Blood, 2002). It can contain different types of information, such as personal, public, commercial, and political information. Du and Wagner (2006) describe three generations of blogs that have evolved during recent years: 1) personal diaries, written with the aim of allowing people without extensive technical knowledge to share text content via single-click web publishing; 2) software that allows more inter-weblog communication features, word processing capabilities and multi-media components; 3) weblogs with new tools embedded to enhance productivity and to further improve connectivity on the web. The third-generation weblogs (or application blogs) are run with the aim of connecting and translating physical activities into the digital world and continuing real-world relationships (e.g. WordPress or Blog.com).

2.6.1.3 Micro-blogging

Micro-blogs enable the online sharing of short pieces of information through the web, mobile phones, and third-party applications. They can also provide links to other sources of detailed information. They provide a platform to share “what’s happening now” (Twitter, 2010) in real-time from people who are involved in newsworthy events, crises, or natural disasters (Grove, 2010). As a result, people can follow news written by people of interest. The power of micro-blogging has increased substantially. Twitter is the “best-known publicly accessible Micro-blogging application” (Loudon and Hall, 2010) and the leading micro-blogging SM had over 336 million monthly active users in a quarterly of 2018 (statista, 2019), getting approximately 500 million tweets per day. Interestingly, as (Dybwad, 2010) shows, the spam volume in Twitter is as low as 1% per day. It is a mechanism for advertising through word-of mouth (Asur and Huberman, 2010).

Micro-blogging websites are also widely embedded into other applications and updated by means of these applications (Arthur, 2010), and micro-blogs’ widespread

nature allows micro-blogging to be used as a tool to forecast future results in different fields, such as economic, politics and health (Asur and Huberman, 2010).

2.6.1.4 Forums (message or discussion boards)

A forum, or message board, is an online conversation site where people converse in the form of posted messages. A discussion forum is hierarchical or tree-like in structure: a forum can contain many sub-forums, each of which may have several topics. Within a forum's topic, each new discussion started is called a thread (each of which have a topic) and can be replied to by many people. The difference between chat rooms and forums is that messages in forums are often longer than one line of text, and are at least temporarily archived. Moreover, depending on the access level of a user or the forum set-up, a posted message might need to be approved by a moderator before it becomes visible.

2.6.1.5 Content communities

Content communities are designed for the sharing of media content, including text (e.g. BookCrossing, sharing books), photos (e.g. Flickr), videos (e.g. YouTube), and PowerPoint presentations (e.g. Slideshare). Content communities do not necessarily require sharing through a personal profile page and people can freely upload content. These sites usually have rules to ban and remove illegal content such as copyright-protected materials.

An example of these sites is YouTube, which serves over 100 million videos per day. Given such high levels of popularity, many corporations use them for promotional material, recruiting videos, keynote speeches and press announcements.

2.6.1.6 Instant Messaging

Instant Messaging (IM) and chat are among the more traditional tools in SM. IM allows real-time conversation and information sharing for multiple users on low bandwidth. Some of its unique characteristics are the real-time exchange of data, the ability to hold a contact list, the ability to decide upon whether your online presence is (in)visible, and the provision of the capability to simultaneously communicate in real-time with more than one audience (Zhang and Fjermestad, 2008). It is currently widely used in organisations to create a network and facilitate information exchange.

However as there are also some drawbacks, mostly due to security issues, some companies are still reluctant to use these methods as a medium for connection between their employees. Yahoo Messenger or Skype are some of examples of this category.

2.6.1.7 Social Network Site (SNS)

SNSs are websites that support existing social networks or form new networks amongst people of particular interests, activities or political views, allowing their social networks to be visible (Boyd and Ellison, 2007). Some sites attract diverse audiences while others serve people of similar interests (Boyd and Ellison, 2007). These sites provide a locale for the creation of a public profile and the searching of said profile and the connections of others. The next step is the sharing of information (visual, aural and textual) on the site, which is then followed by upcoming communications of so-called 'friends' (as is the case on e.g. Facebook, LinkedIn, Myspace, Dailystrengt, CaringBridge).

2.6.1.8 Mobile Social Media

Kaplan and Haenlein (2010) define mobile social media as mobile marketing applications that work by allowing users to generate and share content. There are four types of mobile marketing applications, depending on user location-sensitivity and time-sensitivity. These four types are known as group tester, location aware, dating service, media share. Examples of these applications are WhatsApp, FourSquare, Viber and Telegram.

2.6.1.9 Virtual world and online social gaming

Virtual world applications offer three-dimensional platforms in which users can be represented by avatars and communicate and interact with one another as they would in real life. In this way, they allow for the highest level of social presence and media richness. These applications operate in two forms. First, virtual game worlds, which have strict rules for players to take part in a multiplayer environment (MMORPG). Examples platforms are Microsoft's X-Box and Sony's PlayStation. The second group, known as virtual social worlds, are less strict with rules and allow participants to behave more freely. These applications allow wider interactions and unlimited ways of self-presentation (Kaplan and Haenlein, 2010, Kaplan and Haenlein, 2009). A well-known example of virtual social world is Second Life.

2.6.2 Social media for health and care

The growth of academic publications on SM in health and social care sector shows that health and care have been affected by SM. An increasing number of SM websites providing service to health and care is further evidence of that influence. Governments have also been changing their approach to the delivery of health and social care by trying to identify ways and promote use of technology in this sector. In particular, countries with increasing elderly populations are looking for ways to deliver health and care to elderly people through systems known as Telehealth and Telecare. SM plays an important role in such systems. SM can change people's experience with healthcare. SM applications (e.g. wikis, forums and SNS like Facebook and LinkedIn) make the interaction around health issues faster and more accessible. Tasks like searching and sharing experience, the validation of information, hearing advice and treatments received by others are examples of interactions facilitated by SM (Fox, 2011a, Scafield et al., 2010, Fox et al., 2005). As Fox et al. (2005) note, the associated consequences include the emergence of online expert patient groups and the growth of communities around particular health conditions and states, such as Alzheimer's disease (White and Dorman, 1999), cancer (Turner et al., 2001), Asperger's syndrome (Mitchell, 2003) and childhood genetic disabilities (Schaffer et al., 2008).

Griffiths et al. (2012) believe that SM is developing into a source of medical opinion. Patients' semi-professional knowledge of their health condition is developed through their presence in online communities and groups. It changes patterns of health and illness in communities and alters access to health interventions (Griffiths et al., 2012). The quality of life for elderly people can be also improved by SM due to increased publication of new ideas and new practices (Nef et al., 2013). Professional bodies in North America (AAMC, 1999) and Europe (GMC, 2009) have broadly regarded this as good communication tools for delivery of health care (Street Jr et al., 2009). Leist (2013) investigated SM websites and found that they improved applications such as discussion boards, with these having the ability to be used for many clinical purposes. One goal is to deal with patients or their relatives in relation to their condition through the use of information about prevention, diagnosis and treatment.

In 2018, 86% of British adult citizens accessed the Internet every day (National-Statistics, 2018). On these individuals, 43% searched for health or medical information. In the USA, amongst the adult internet users, 72% searched for health information (Fox and Duggan, 2013). These figures are rising yearly and show an increase in the search for online health information. Studies show that when an individual is faced with a health challenge, there is sometimes an option to find peers, with this being one of the most important sources of information for influencing their actions and decisions (Lieberman et al., 2003, McGettigan et al., 2001). Berkman and Glass (2000) identified five processes facilitated by SM and relationships that affect health behaviours and outcomes:

- *Social influence*: the way the presence, acts or expectations of others influence the way one behaves (Latane, 1981).
- *Social engagement and attachment*: how social network relationships increase engagement and contact with other people (Amichai-Hamburger and McKenna, 2006).
- *Social recommendations*: how social network structure affects the sources of knowledge used by people and changes the access to resources and recommendations (Pirolli, 2009).
- *Social contagion*: the way in which health behaviours and non-infectious conditions (such as happiness, obesity, depression) may be ‘transmitted’ by ‘person-to-person spread’ across social networks (Fowler and Christakis, 2008).
- *Social supports*, such as emotional, functional, and informational assistance, are well-documented in relation to their ability to influence one’s health significantly (Berkman and Glass, 2000).

The number of elderly adults who use the Internet, and SM is continuously rising. As of April 2012, half of the adults aged over 65 years in the USA were online, and one third of online seniors (34%) used social networking sites like Facebook and LinkedIn (Zickuhr and Madden, 2012). Such applications are also known to be beneficial in delivering Telehealth and Telecare services (Lee et al., 2012).

SM could lead to positive outcome on users’ social integration (Shklovski et al.). This could in turn lead to easier access on the part of the older population to online health

information. Hence, there is a possibility of lessening health inequalities. The Internet is providing a new context for this to happen, free from the constraints of traditional health care (Rocha, 2010).

Through social networks, patients assemble health-related information that has the potential to compete with and to extend the reach of professionally assembled information. However, there are concerns about the reliability of health information shared through SM. While there is evidence of valid information shared by the public (Scanfeld et al., 2010), there are also studies that question the validity and quality of data shared in SM (Cobb and Scotton, 2013). So one needs to be careful and critical in relation to the use of such publicly shared information (Adams, 2010b).

In the next section, I discuss the benefits and opportunities of SM as tool as well as the threats, risks and limitations of SM as it may apply to the health sector.

2.6.3 Benefits of social media for health

Traditional websites (web 1.0) work like a broadcasting medium. They distribute information in one direction, and so the model is related to publishing. With the development of web 2.0, a revolution happened in the world of the net such that users came to play a vital role in making this happen. SM applications yield the opportunity for their users to generate and control the content of the websites. In other words, SM enable users to generate data and allow peer-to-peer or many-to-many discussion as opposed to traditional information publishing websites (Nakayama et al., 2009, Adams, 2010b, Hwang et al., 2010, Moorhead et al., 2013). SM is developed as a new channel for communication between users to connect to each other. Research has therefore highlighted numerous benefits of SM. The widely discussed benefits are described in this section.

2.6.3.1 Improved health communication

Moorhead et al. (2013) show that SM has increased interaction for health communication purposes. The main benefits of using SM are for the general public, patients and health professionals. Many publications report that the advantages of SM for communication in health relates to the widening of access to health information by various population groups, across groups relating to age, education level, race or ethnicity, and locality, especially in comparison with traditional communication

methods (Moorhead et al., 2013, Chou et al., 2009b, Kontos et al., 2010a, Scanfeld et al., 2010).

Reports show that SM can facilitate access to wide health information easier and is cheaper for a range of people, such as younger people, ethnic minorities, and lower socioeconomic groups in comparison with traditional methods (Chou et al., 2009b, Kontos et al., 2010a, Lariscy et al., 2010, Egan and Moreno, 2011a, Egan and Moreno, 2011b, Lord et al., 2011, Ralph et al., 2011). Another important aspect of SM in health communication is the provision of valuable peer, social, and emotional support for the general public (Moorhead et al., 2013, Lupianez-Villanueva et al., 2009, Ahmed et al., 2010, Colineau and Paris, 2010, Farmer et al., 2009, Moen et al., 2009, Nordqvist et al., 2009, O'Grady et al., 2012, Selby et al., 2010, Setoyama et al., 2011, Van Uden-Kraan et al., 2011) and patients (Beard et al., 2009, Frost and Massagli, 2008, Gajaria et al., 2011, Greene et al., 2011, Hwang et al., 2010, Liang and Scammon, 2011, Moen et al., 2009, Nordfeldt et al., 2010, Nordqvist et al., 2009, O'Grady et al., 2012, Scanfeld et al., 2010, Takahashi et al., 2009, Timpka et al., 2008, Moorhead et al., 2013).

This communication can help and influence health behaviour (e.g. smoking cessation). Some SM websites enable patients to communicate with each other and enable them to share information and experience about health issues (e.g. Patientslikeme, Babycenter). Colineau and Paris (2010) reported that people also use health social networking sites to discuss sensitive issues and complex information with health professionals. In public health surveillance, SM can provide communication in real time and at a relatively low cost (Chew and Eysenbach, 2010, Jennings et al., 2009, Scanfeld et al., 2010, Scotch et al., 2008, Signorini et al., 2011, Weitzman et al., 2011, Gao and Feng, 2016, Paul and Dredze, 2017). The relationship between real life and SM communication is yet unclear, however (Nef et al., 2013) and only in some cases are the findings similar for real-world and SM communication (Leist, 2013). For instance, Ellison et al. (2007) reported a positive relationship between SM users and maintenance and the creation of social capital. In summary, Table 2-2, created by Moorhead et al. (2013), shows the usage and benefits of SM in health communications. Whilst insightful, the current literature also falls short of explaining the differences

between SM health communication and face-to-face health communication. This includes explaining the new tensions and challenges caused by this new approach to communication.

Uses of SM for health communication users	General public	Patients	Health professionals
Providing health information on a range of conditions	✓	✓	✓
Providing answers to medical questions	✓	✓	✓
Facilitating dialogue between patients to patients, and between patients and health professionals		✓	✓
Collecting data on patient experiences and opinions		✓	✓
Use for health intervention, health promotion and health education	✓	✓	✓
Reducing stigma		✓	✓
Providing online consultations		✓	✓
Benefits of SM for health communication users (general, public, patients' health professionals)			
Increasing interactions with others	✓	✓	✓
More widely available, sharable and tailored information	✓	✓	✓
Increasing accessibility and widening access	✓	✓	✓
Peer/social/emotional support	✓	✓	✓
Public health surveillance	✓	✓	✓
Potential to influence health policy	✓	✓	✓

Table 2-2- Uses of social media for health communication users (Source: Moorhead et al. (2013))

2.6.3.2 Heightened family and friends communication

SM changes the communication patterns and preferences of the elderly population (Yuan et al., 2016). In addition to increasing the communication pertaining to health-related issues, SM enables individuals to keep up-to-date with their friends and families. Gibson et al. (2010) reported that the main benefit of Facebook is to keep up-to-date on what is going on among family members and friends. Elderly population derives social connectedness through Facebook (Sinclair and Grieve, 2017). Béland

et al. (2005) also reported that SM represents a new communication channel for maintaining relationships between the growing population of elderly and their peers and families. Use of these applications may serve as motivation for older adults to connect with geographically remote grandchildren or family (Gibson et al., 2010). On the one hand, Brandtzaeg (2012) show that the use of SM complements social contact, and could lead to higher levels of social contact overall. On the other hand, there is also evidence that heavy internet use can lead to decreases in the rates of visits by family or friends (Nef et al., 2013). Some authors claim that using the Internet leads to the emergence of a new social circle (Turkle, 1997, Kraut et al., 2002), and the creation of long-lasting online social relationships (McKenna et al., 2002) and that it augments involvement in existing communities by providing new social spaces for communication (Katz and Aspden, 1997, Wellman et al., 2001, Nef et al., 2013).

Karimi and Neustaedter (2010) reported a large variability in communication behaviour. They propose four archetypes: the living newspaper that maintains communication by relying on new technology; the high-tech social hub who are always online; the free-spirited bird that maintains a spontaneous lifestyle and interaction; and the isolated communicator who expends a high degree of effort to maintain communication without these efforts always being reciprocated.

In general, some contradictions in benefits of SNS as they relate to family are reported. This could perhaps be due to the various ways in which they are used. As Barker (2012) suggests, some people use these applications for peer communication while others use them for social compensation. In this way, the key advantages of SM are better reach, increased interaction, low cost, and the capacity to communicate quickly. They also allow some level of asynchronous communication by making messages available for later retrieval. Whilst SM offers new patterns and forms of communication between the elderly population and their family and friends (Yuan et al., 2016), future communication potentials of SM remain to be discovered.

2.6.3.3 Sharing and exchanging information

Another benefit of SM is that users can share information or experience with other users. This enables individuals to exchange information on behalf of themselves or of others on subjects such as the experience of bodily symptoms, clinical diagnosis and

treatment options, adverse treatment effects, sources of medical evidence, experiences with individual providers and opinions on quality. These experiences are exchanged through websites, web forums, blogs and web-based social networks. Examples of such sites include Diabetes UK and Arthritis Care and NHS Choices. In this way, patients voluntarily share personal health data and obtain access to medical knowledge and advice outside the scope of the doctor patient relationship. This information also allows professional networks to have greater access to health data sets and to the skills needed to analyse them. This gives users the ability to give and obtain feedback on interactions. It also serves as valuable evaluation of data on the design or refinement of further health promotion efforts (Griffiths et al., 2012).

2.6.3.4 Reducing isolation

As discussed above, one of the significant issues that threatens the older or disabled population is isolation from society. SM can reduce social isolation (Erickson, 2011, Vošner et al., 2016). Older people have the motivation to use SM to maintain contact with other family or friends as a means of reducing loneliness. Farkas et al. (2010) found SM dialogues can serve as a means of reducing social isolation, loneliness, and promoting the involvement of older people in their family life. Particularly for senior citizens with limited mobility, SNS may help them to maintain connections (Erickson, 2011, Lüders and Brandtzæg, 2017). This does not mean that SM can replace face-to-face communication (there is very limited knowledge on this); rather it means that it creates a new form of communication that helps people reduce loneliness.

SM might be helpful for older people or some particularly disabled people with limited mobility or those that would otherwise become more isolated due to communication difficulties (Erickson, 2011). Cornejo et al. (2010) give evidence that SM can enable such people to keep in touch with other family and younger people. An intergenerational interaction view is very beneficial for and appreciated by both sides. Tsaousides et al. (2011) investigated people with traumatic brain injury and found that SM applications were used by those people (Mittal et al., 2012).

There is evidence that SNS might enable older people to stay in touch with younger generations (Williams et al., 2005, Nef et al., 2013, Mesch, 2012, Hill et al., 2015) and that this intergenerational interaction is beneficial for and appreciated by both sides

(Cornejo et al., 2010). Despite all the evidence that SM could lessen isolation, there are also some arguments that point to the possibility of SM making people less connected in the physical sense.

2.6.3.5 Reducing cost and time

Compared to traditional media, SM-based health information broadcasting efforts were low in terms of cost (Chou et al., 2013). The availability of the Internet is much more popular in comparison with information searches in libraries. In this way, it is much more cost effective. Additionally, SM can provide the information and experience validated by other users offered in a much cheaper and easier way which benefits the low socioeconomic status populations (Albright et al., 2005, De Nardi et al., 2016).

2.6.3.6 Social support

Leist (2013) found that research shows that the main sources of motivation for elderly people to participate in SM are enjoyment, engaging in social contact, and providing and receiving social support (Pfeil et al., 2009, Xie, 2008b, Leist, 2013). Users value SM as social support for computer-mediated services such as anonymous, asynchronous, and text-based communication. Users with similar backgrounds or experiences that have participated in online communities or forums on depression, cancer, alcoholism or caregiving issues have found effective and valued social support. Aside from satisfying the need for social contact, SM can enable users to provide and receive social support, both of which sources of support may in turn contribute to life satisfaction and wellbeing (Leist, 2013).

2.6.3.7 Patient empowerment

The new SM applications and their content can be controlled by their users. Moreover, patient groups operate and work on new platforms of SM for collaboration with professionals. This has resulted in a change of patients-professional relationships and interactions (Griffiths et al., 2012). Moreover, users can control their profile to modulate who can access or see their information. These aspects of social media can offer empowerment and self-efficacy to the elderly (Barak et al., 2008). The feeling of empowerment in decision-making leads to positive health behaviour and healthier lifestyles (Samoocha et al., 2010, Korda and Itani, 2013). This empowerment, in turn,

gives confidence to patients in asking questions of professional and provides them with information to help them manage their conditions (Fox et al., 2005, Jacobson, 2007).

2.6.3.8 Health promotion

Scholars also have published a large body of literature on the use of SM (or the “participative internet”) as a powerful tool for interactive health promotion (Schein et al., 2010, Jones and Fox, 2009, Smith, 2010, Korda and Itani, 2013), such as smoking cessation, dietary interventions, physical activity, and sexual health wellbeing (Vance et al., 2009, Norman, 2011, Chou et al., 2009a, Gabarron and Wynn, 2016).

These studies highlight growing opportunities for health interventions to utilise an array of innovative measurement tools for assessing dissemination, exposure, engagement, and effectiveness. In fact, as more users obtain experience of Web 2.0, methods and approaches are becoming more sophisticated (Chou et al., 2013). For instance, peer social support provided by SM users can be used as a beneficial strategy to employ in weight management programmes (Jane et al., 2018). However rigorous privacy protocols need to be put in place in order to maximise the associated benefits (Jane et al., 2018).

Although many studies discuss the potential for SM in health care, scholars also highlight some risks and limitations associated with SM. This section will discuss these limitations and threats in more detail.

2.6.3.9 Limitations in communication

In the previous section, I outlined the benefits of communication of SM but this type of communication also leads to new challenges and limitations. Moorhead et al. (2013) found 12 limitations of SM for health communication (Table 2-3) among the general public, patients, and health professionals. The main recurring limitations of SM relate to the quality of discussions (Adams, 2010b, Adams, 2010a, Friedman et al., 2011, Hughes et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010), the unreliable nature of the information on health (Adams, 2010b, Adams, 2010a, Farmer et al., 2009, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010) and problems with confidentiality and privacy.

Limitation of SM for health communication users	General public	Patients	Health professionals
Lack of reliability	✓	✓	✓
Quality concerns	✓	✓	✓
Lack of confidentiality & privacy	✓	✓	✓
Often unaware of the risks of disclosing personal information online	✓	✓	
Risks associated with communicating harmful or incorrect advice using SM	✓	✓	
Information overload	✓	✓	
Not sure how to correctly apply information found online to their personal health situation	✓	✓	
Certain SM technologies may be more effective in relation to behaviour change than others	✓		
Adverse health consequences	✓		
Negative health behaviours	✓		
SM may act as a deterrent for patients from visiting health professionals		✓	✓
May not currently use SM to communicate to patients on a frequent basis			✓

*Table 2-3 - Limitation of SM for health communication users
(Source: Moorhead et al. (2013))*

SM are informal, unregulated tools for information collection, exchange, and promotion. Hence, the obtained and shared information has variable quality and consistency (Adams, 2010b, Adams, 2010a, Farmer et al., 2009, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010). Similar issues exist amongst traditional internet websites. However, the interactive, unregulated and uncontrolled nature of information exchanged on SM amplifies this. Some aspects of reliability could be controlled by automated processes to a certain extent (Adams, 2010b). In this respect, some types of technical processes or aspects, such as spam control and the quality and trustworthiness of content, can be monitored. Moreover, much of the information shared is applicable to a certain persons' situation. So, when users of information want

to use data produced and shared on SM, they need to be careful in applying them to their own health condition (Adams, 2010b).

Moreover, to enhance the “media richness” (Kaplan and Haenlein, 2010) of SM for health communication, effort is required to reduce ambiguity and uncertainty. One way to do this is to combine different resources in one internet location to add to the reliability of information. In this way, as users interact and share information, they can compare and triangulate the obtained information to assist them in distinguishing reliable from unreliable information (Adams, 2010b).

2.6.3.10 Privacy and safety

Another limitation is that information posted online can be viewed by a large number of people that can in turn lead to a breach of privacy (Nef et al., 2013). Hence, careful examination of security issues is necessary to protect personal information (Moorhead et al., 2013). According to the existing regulations of health information, health data is inadequately protected by SM websites. For patients who join SM and share their personal information, it is very important to understand who accesses their data (Leist, 2013) to make sure that their data is not used in unintended ways. In some cases, as a result of limited knowledge of appropriate internet use and information disclosure, elderly people may reveal personal information that can be misused.

Conversely, new users often have a sense of loss of control in managing registration and fear that data privacy may be violated (Charness and Boot, 2009, Xie, 2008a). According to various authors, this might be the main inhibitor against SM use by older citizens (Nef et al. (2013)). Similarly, Norval (2012) reported that privacy concerns and a lack of trust is a concern for older persons. The results show that people with this fear also expressed that they did not see the benefit of SM in any way.

Leist (2013) has two suggestions to overcome the privacy and safety issues. First, users should understand the terms and rights of online SM where they share their personal information, and they need to understand how SM uses or distributes these data. However, due to the complexity of the current way in which the terms and conditions are stated, there is very limited evidence that they can actually be of much use for the

users. Second, it is necessary for users to have knowledge on functionalities to engage in consuming, creating and sharing content.

The safety of SM data are complicated because the degree of impact of SM might not be captured in an easy way due to the ‘viral’ nature of the network (Lau et al., 2011). The complexities of relationships and the complicated nature of the growth of SM contents requires that numerous factors be measured to understand the influence that information may have on patients and information users (Lau et al., 2011).

2.6.3.11 Bad information

As SM are applications that are dynamic and two-way in nature, and relatively unregulated, various ways of information collection, sharing and promotion can effect the quality of associated data (Adams, 2010b, Adams, 2010a, Clauson et al., 2008, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010, Moorhead et al., 2013). Cotter (2006) stated that, in various networks, bad and incorrect information can distribute fast and drive out good and correct information. Galeotti and Goyal (2010) also show that most users access their information from a limited range of sources and hence they do not compare the correctness of the information offered by these different sources. For health-related information assembled through social networking to be of value for improving health and health care, longitudinal consistency of information will be needed, such as following-up in relation to volunteered personal data, yet privacy also needs to be respected (Griffiths et al., 2012).

2.6.3.12 Trust

The wide range of data on the Internet offers users access to a range of medical information. This gives patients the opportunity to access the same medical information as professionals. However, the public and patients do not have professional expertise and this can lead to considerable challenges for them in knowing what information to trust and use (Powell et al., 2011). Furthermore, SM tools allow lay-users to share information regardless of quality. This issue also exists in traditional websites but the interactive nature of these tools has accentuated these issues (Moreno et al., 2007).

Therefore, there is a potential to share harmful information in SM application such as forums in which members publicly distribute their knowledge. However, despite the discussion in relation to this issue as it effects children and younger people, the potential threats of SM use have not yet been well researched for older people (Leist, 2013).

2.6.3.13 Reduce activity and isolation

As mentioned in the previous section, the use of SM can be beneficial for physically impaired users but it may be a threat as it could reduce their activity. For instance, Pantic et al. (2012) reported that frequent Facebook use may lead to depression and may reduce the time for outdoor physical activity as well as the time for real social relationships (Lucas et al., 2011).

SM can also contribute to depression and it has been directly linked to a sense of loneliness and social isolation (Alpass and Neville, 2003, Ayalon and Shiovitz-Ezra, 2011). However, there is no evidence that this group of isolated people would be more communicative and social in the absence of SM. Moreover, in the case of older people, the results are mixed. Research shows that some elderly people join SM to maintain a supporting relationship and reduce loneliness and isolation, but, at the same time, this group of individuals should maintain face-to-face contact as SM is not a replacement for all types of contacts (Eggermont et al., 2006).

2.6.4 Usage of social media by older adults

Statistics show that the number of older adult who use SM are increasing globally. Madden (2010) reported that SM use has grown significantly across all age groups, with older people showing special enthusiasm in relation to the use of new networking tools. In this respect, SM use among internet users over the age of 65 has almost doubled (22% in April 2009 and 42% in May 2010). Further research shows that SM use among internet users aged 65+ has grown from less than 5% in 2006 to more than 25% in 2016 (Figure 2-10). Moreover, during the same period, the use of these tools has grown 100% (from 13% to 26%) among people aged 65 and over.



Figure 2-10 SM usage among seniors (age 65+) between the 2006 - 2016

Pew Research Centers in the US (Figure 2-11) show that the population of people over the age of 65 who use SM has increased 43% from February 2005 until May 2013 (Brenner and Smith, 2013).

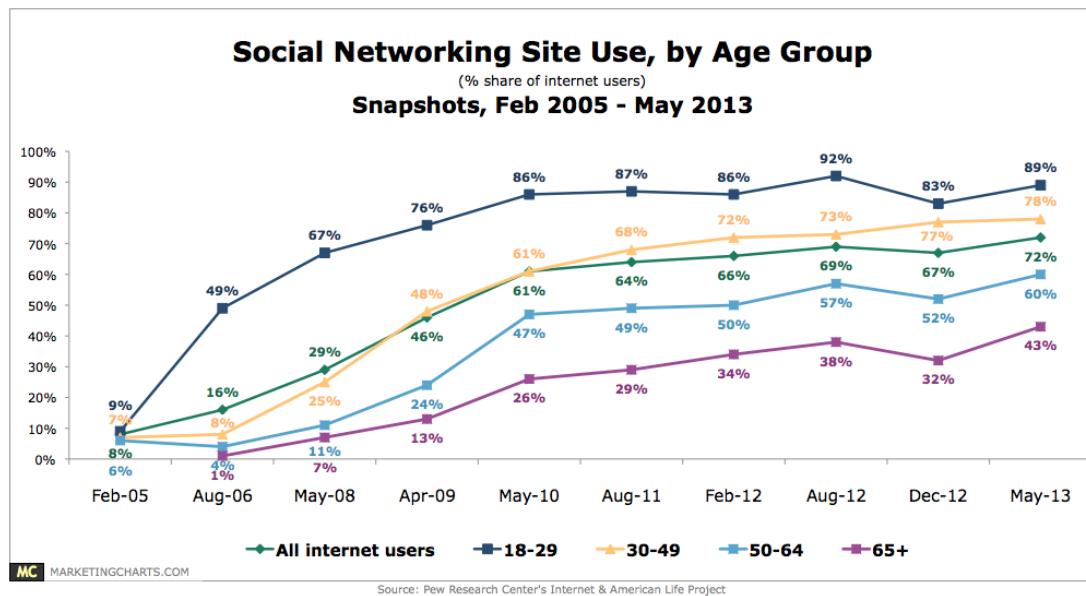


Figure 2-11 – Social media sites use by age group

The statistics show that the population of older people who use SM is increasing (eMarketer, 2013) - Figure 2-12). Since 2016, the overall rate of growth has steadied in a downward fashion. However, there is a massive growth by those aged 50 to 64. There was also a sudden increase after 2014 for those aged 65+ (Pew-Research-Center, 2018).

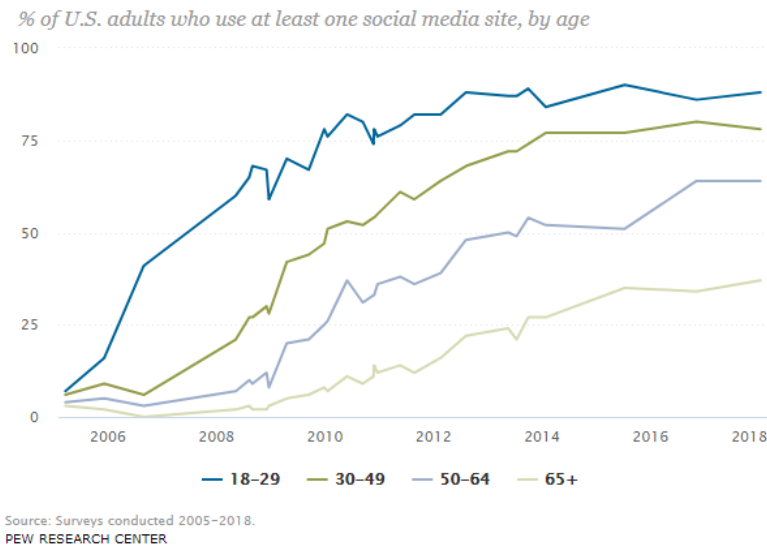


Figure 2-12 - US Social networking user

2.6.4.1 The challenge of using social media for older adults

One of the barriers against older adults using SM is the limited user-friendliness of these applications for this age group (Leist, 2013). In some cases, it seems that web designers do not take into account the particular needs of older adults or disabled people (Chou et al., 2010). Nef et al. (2013) reported that the purpose of SM was difficult for older participants to grasp. Moreover, older people may suffer from some functional limitations (Charness and Boot, 2009). For instance, blindness may, despite assistive technology, prevent the use of online SM if no further assistance is available. However, it should also be mentioned that, more recently, there has been a growing number of disabled people who are actively working to improve the accessibility of such technologies (Heart and Kalderon, 2013).

Lee et al. (2011) introduced different kinds of apprehended barriers for the elderly in the use of SM. They include difficulties whose nature is intrapersonal (e.g. 'I am too old for it'), functional (e.g. related to memory decline, spatial orientation), structural (e.g. 'It costs too much to own a computer'), and interpersonal (e.g. 'no one teaches me how to use it').

Some studies show that the use of SM in societies in relation to some specific diseases, such as traumatic brain injury (Tsaousides et al., 2011) and stroke (Mittal et al., 2012), can be highly challenging. Additionally, the process of signing up to SM applications and filling in the profile can be a complicated task for the elderly (Leist, 2013). Overall,

79% of older SM users state that current tools do not cater for their particular needs and circumstances and hence it is important that SM designers take the needs of elderly adults into consideration (Chou et al., 2010). However, although there are some sophisticated approaches that help designers understand the limitations of older people, there is as yet limited knowledge of many of the specifics needed for the design of such applications for older populations. This could be because of both the newness of the concepts and approaches as well as challenges in eliciting information from older people. Despite this lack in the majority of SM tools, there are a limited number of applications that are specifically designed for older people (Farkas et al., 2010).

Other issues in need of consideration are: access to the Internet (the percentage of individuals with access to the Internet is low in many countries); the limitation of information on the influences of user interface design on user acceptance for older people, particularly with regard to standard and universal designs (Jaeger and Xie, 2009); and the absence of sufficient studies on the ways in which SM is perceived in the wider web content (Leist, 2013).

To summarise, despite the growing population of elderly people and the various uses of SM by this group, there are a number of problems in doing research in this field that require careful consideration. The literature is biased toward publishing the current benefits (Hunsaker and Hargittai, 2018) and pays insufficient attention to future uses and services. The literature also disregards effects such as new conflicts that may arise from the existing and new uses of SM by elderly people.

In this chapter, I have presented the necessary background for the rest of this thesis. This includes a formulation of the problem based on demographic data and the aging population, a revision of the definitions, and an exploration of the literature on the advantages and disadvantages of SM for health, with a particular focus on older people.

We can categorise SM for health based on its design objective into three groups: a) SM designed and developed for general purpose use that are now used for health and care such as Facebook Groups; b) SM designed and developed for health purposes based on the concept and use of generic SM as their backbone, such as 3D Doctor,

with these making use of Skype to connect patients to their doctors; c) applications designed and developed specifically for health and care purposes using concepts of SM such as HealthUnlocked. SM can enable social integration of the elderly with their families, friends, and community, which can lead to a range of further benefits (Shklovski et al., 2006), such as improved understanding of conditions and experiences, enhanced communication with professionals, reduced isolation and costs and patient empowerment. At the same time, some authors believe that, despite these benefits, many older people are unaware of the purposes and potential benefits of SM (Gibson et al., 2010, Norval, 2012, Maier et al., 2011, Nervik et al., 2011). Although there is a large body of papers in health about the uses and benefits of SM with regard to reaching underserved and marginalised populations, and decreasing the digital divide and information disparities, the claimed potential has not been sufficiently demonstrated so as to be used in actual practice (Nef et al. 2013). Limitations in empirical research show the need for further work to examine how socially excluded populations who have health issues can benefit from SM in health.

There is a wide range of studies around the impacts of SM tools on young people and adults. More recently, there have been rising numbers of publications presenting new ideas and new approaches on how SM can improve the quality of life for older adults (Nef et al., 2013). However, there are a number of shortcomings in the current trends of studies. Primarily, many studies adopt a quantitative approach (Hunsaker and Hargittai, 2018), using questionnaires and online surveys. Whilst beneficial in providing a number of users and uses, they fall short of explaining the reasons for non-use and the resulting problems, such as social exclusion (Seifert et al., 2018). They also rarely identify future opportunities offered by SM for new health services. Accordingly, drawing on the current literature, it is also hard to understand why current SM fail to provide for some of the needs of older people.

Furthermore, studies indicate that there are particular concerns about some norms, such as privacy by older users (Gibson et al., 2010, Chou and Edge, 2012, Norval, 2012). However, they fall short of explaining the ways to overcome such concerns.

Moreover, studies such as those conducted by Chou et al. (2010) and Nervik et al. (2011), looking at the actual usage of SM by older adults, can also lead to

distinguishing differences between implications of these tools for older versus younger users. Accordingly, there are also differences with respect to the ways of use with regard to the abilities and nature of communication between different age groups. For instance, the presence of less text seems to be an important factor for older adults as they tend to read everything displayed on the screen, while younger people skim through and skip much of the text. There were also some debates around the benefits of touchscreens as the interface technology (Teixeira, 2011, Tsai and Chang, 2009), or the use of smartphones or tablets over desktop computers or laptops. Hence, there is a significant gap in the literature on the practical uses and benefits of SM for improving the health of elderly people. These issues and dissimilarities of the elderly population in comparison with younger generations (in terms of concerns, benefits, uses, and etc.) point to avenues for future research.

Finally, whilst the literature points to uses of SM for the elderly population, it fails to highlight and explain the new conflicts arising as a result of the use of this new medium. Future research should go beyond the use discussed previously by seeking to understand the associated positive and negative effects (Giustini et al., 2018). Careful study designs that examine the details of actual use and any resulting competitions and conflicts of interests require to be adopted in future research.

Chapter 3 - Methodology

3.1 Introduction

In this chapter I present the aim of this study and describe the approach and methodologies used to conduct the research project.

3.2 Research aim

This study explores the role of SM in enabling co-production of health and care as they are integrating to improve coordination between the different formal and informal bodies. In this study, I focus on co-delivery and of co-design of services.

I described two very important matters of today's society in the previous chapter: first, family and carers play a significant role in the delivery of health and care and gain valuable expertise while providing care. Second, SM is becoming a powerful tool in the daily lives of people. Putting these two together, I investigate the role of SM in co-production of health and care delivery and its effect on the existing work processes during the integration of health and care. In other words, knowing that SM enables us to be more connected, I address the question of how this affects co-production of services in delivery of health and care for patient groups with long-term needs and conditions.

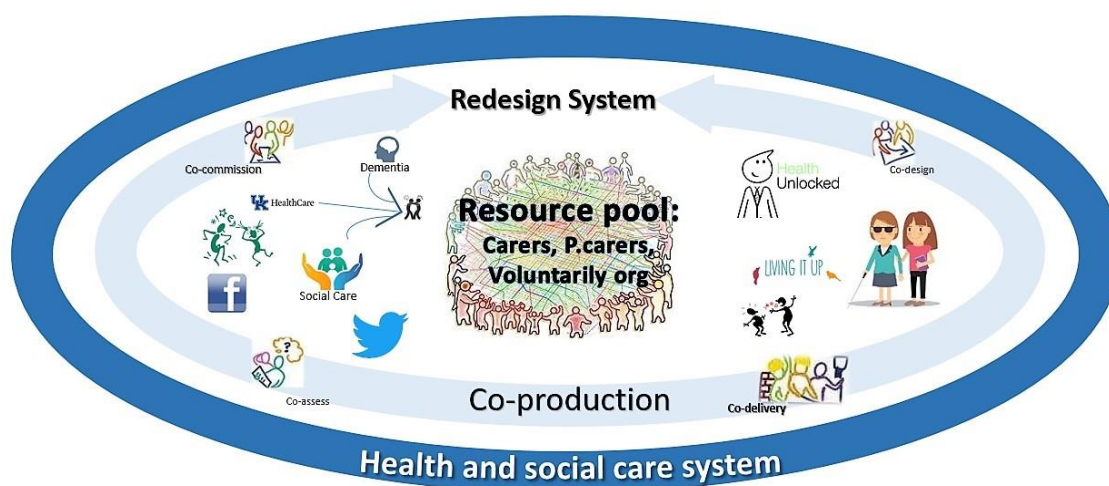


Figure 3-1- Conflict and issues surrounding health and care system, redesigned by co-production (Author's own, 2017)

To explain this in broader terms, we see that the health and care system is being redesigned through co-production (Scottish-Government, 2012). We have a pool of carers (CPR) that is associated with a high level of conflict and competition (Figure 3-1). SM enables co-production (co-delivery of service) in this field. The result is, on one hand, solutions being formulated in relation to some existing conflicts and meeting demands. On the other hand, it is the creation of new forms of competition and conflict. The intention is to investigate this field and its emerging benefits and problems in detail.

3.3 Research objective

In the previous chapter, I highlighted some of the possible uses of current SM in supporting the elderly in relation to health and care. The coordination of the massive informal carer resource with the formal health and care system can lead to reductions in the cost of care to the NHS and improvements in the quality of life (QoL) of the elderly. In order to do this, I primarily need to characterise the modes of co-production to see the possible range of opportunities. I then investigate the broad range of opportunities offered by the current tools to support the current health and care services. Also, more importantly, I go beyond the current applications and current health and care services and envisage what changes can be made to the existing tools to achieve my earlier stated aims. I investigate how this change will create, modify or resolve existing conflicts. To do this I propose a two-dimensional model (Table 3-1) that depicts the broader field of my investigation.

3.4 Research questions

Two main sets of questions will be addressed: what are the current uses of SM in health and social care? And how can SM be reshaped to enable (and reshape) health and care co-production?

I consider a typology of opportunities and limitations of SM for health and care: existing health and care services bundles with (1) existing or (2) new SM tools, and new health and care services bundle with (3) existing or (4) emerging SM tools (Table 3-1).

Health and Care

		Current Service	Change Services
		Use of current SM in the existing situation (1)	Current SM help to change health and care services (2)
Social Media	Current App	New SM to cater for the current health and care services (e.g. LiU) (3)	New SM with new health and care Services (4)
	Redesign		

Table 3-1- Health and care with social media

This study therefore addresses four main sets of questions:

1. How does current SM support co-delivery of current health and care services? (Chapter 4)
2. How can current SM lead to co-delivery of new services? (Chapter 5)
3. How can SM be reshaped to make co-delivery of services possible? (Chapter 6)
4. How can SM be reshaped to make possible co-delivery of new services and improve the integration of health and care services? (Chapter 6)

3.5 Methodological choice: multimethod qualitative research

I propose to use a qualitative approach in this study because it offers an in depth understanding of the research environment (Walsham, 1993). It presents details of the connections between contexts, contents and processes (Pettigrew, 1990). In qualitative research, the investigator stimulates views and observe the actions of actors engaged in the study’s situation (Kaplan and Maxwell, 2005) , thus enabling the research to achieve a deeper understanding of the social context as it is shaped and seen by its constructors (Kaplan and Maxwell, 2005, Myers, 1997). The aim of my study is to understand the logic and reasoning of actions, and to develop an interpretation of ‘what

is happening here’, which makes qualitative approach most suited as compared to the quantification of results (Kaplan and Maxwell, 2005).

In this research, I will use the ‘cyclical nature’ (Kaplan and Maxwell, 2005) of qualitative data collection and analysis to achieve an iterative understanding of the environment, the actions of people, how they perceive their activities and the associated consequences. The qualitative approach would also enable me to study SM in its natural setting, and make sense of the relationship it has with its users (and non-users) for health and care purposes (Denzin and Lincoln, 1994).

3.6 Theoretical framework

As discussed in the previous chapters, I intend to understand and explain the various dynamics of use of technology in health settings. My focus is therefore on better conceptualising such systems through understanding the views of users as well as comprehending the organisational and personal consequences of their use. In order to do this, I outline the range of possible theoretical frameworks that could be used in this study, and then explain why I have chosen NPT. This is then followed by an explanation of how NPT is used in this study.

When investigating technology adoption and use in healthcare settings, one needs to consider both technical and social dimensions involved in interactions between humans and technologies. One of the most prevalent approaches to study of human interactions with technologies in organisational settings is that of sociotechnical systems. This perspective takes into consideration the multifaceted links and complexities involved in the human-technology-organisation interactions. The sociotechnical approach involves studying systems (such as organisations e.g. NHS, charities, professional care organisations, etc.) with interrelated technical aspects (e.g. SM) and social aspects (e.g. attitudes). This approach has two main principles: 1) the performance of a system (e.g. an organisation is influenced by the interaction of social and technical features ((Mitchell and Nault, 2003)) which may be either linear (cause and effect relationships) or non-linear (complex and unpredictable) in nature (Walker et al., 2008); 2) the optimisation of one aspect (social and particularly technical) increases the complexity of relationships and the likelihood of unpredictable outcomes

(Walker et al., 2008) . In this view, an organisation is not a structure, but rather a set of actions performed by different actors.

Normalisation Process Theory (NPT) provides a ‘middle-range theory’ of socio-technical change (May et al., 2007). It is therefore used as a theoretical framework to allow me to gain a meaningful understanding of the complex socio-technical processes involved in the use of SM tools and services within health and care co-production. Prior to an explanation of how NPT is used to inform this research, I draw on my analysis of theoretical positions that led to the selection of NPT. Sociotechnical systems explain the interaction of society’s infrastructures and behaviours of individuals within the society. On this view, the society and its constructs are viewed as complex socio-technical systems. Explaining the ‘interactions’ is the focus of this theory.

3.6.1 The range of theories

Studying technology in healthcare settings is complex in nature and requires appropriate socio-technical theories in order to capture its various dimensions. A range of different theories have been developed and used across different studies. Here I briefly describe some of the possible approaches and then explain why I have opted for NPT in this thesis.

- 1- Actor-Network Theory (ANT):** ANT is a framework, which considers humans and non-humans as actors, which help us to study the technological infrastructure (Latour, 2005). ANT shows that networks exist between actors but does not explain the reasons for their existence and their power relationships. It is focused on the infrastructure of actor-networks and follows the actors and their roles. As a result, it fails to encounter the role of wider contextual factors and reflect on how the technology is shaped by its human actors. It merely goes beyond a descriptive account of the situation. The complexity of the healthcare sector requires going beyond these limitations.
- 2- Strong Structuration Theory:** Strong Structuration Theory enables investigations into external structures (such as institutions and social relations), internal structures (such as attitudes and skills), acts of agencies, and their

consequences. It argues that structures and agents mutually shape each other. In this theory, the focus is on structures and agents, which is not the focus of the present study.

- 3- Social Shaping of Technology (SST):** SST suggests that technology is shaped by historical, cultural and economic factors. It also shows that technology development occurs as a cyclic process, which includes the evolution of technical and social aspects together. SST highlights the significance of the macro-environment in shaping, implementing, adopting, and using technology (Williams and Edge, 1996). This perspective is very helpful. However, the theory does not provide a systematic account of data collection and analysis.
- 4- Theory of the Diffusion of Innovations:** Diffusion of Innovation relates to the spread (and non-spread) of innovations across various organisations. It explains a wide range of factors in the adoption and acceptance of technologies. In this theory, there is an assumption of linearity in the spread of technologies, which fails to account for how technology goes through several cycles of innovation as users make use of it. Therefore, it falls short of explaining how different actors involved in health settings may coproduce technology, or how they may have various affordances of the same technical products.
- 5- Normalisation Process Theory:** NPT is a widely used framework for the examination of how interventions work in organisations, or other settings. It can be used to explain the processes by which innovations succeed or fail to normalise (meaning to embed) into routine practices of a setting (May et al., 2011). It therefore focuses on conditions of use and user behaviours and as a result it helps to envisage the factors related to adoption as well as sustainability of a technology in a setting (which may be an organisation, a system or a community).

3.6.2 The selection of NPT

I adopt the Normalisation Process Theory (NPT), which is widely used in the field of eHealth. This framework offers an explanatory model, which includes classification, techniques and practices involved in the use of technology in one's life (May et al., 2011). NPT places emphasis on social action, which is the primary point of focus in my research. The key constructions of this theory are observable social mechanisms,

which form the applied workability and integration of some complex technologies (May and Finch, 2009, May et al., 2011).

NPT pays attention to agentic contributions, being individuals and groups act of new or changed modes of practice as they interact with dynamic elements of their complex system. As the aim of this study is to understand the work that individuals and groups perform in order to operationalise SM in their practices while they are acting in a dynamic environment, I use NPT. NPT allows me to explore the changing mechanisms adopted by users for embedding and integrating technologies in complex settings.

I found NPT to be the most suitable in conducting this research. The reason for the selection of NPT is that it enables me to specify mechanisms for the integration of new technologies in large scale societal structures (making it more relevant than ANT). Moreover, it focuses on work practices and things done by users for the embedding of technology (rather than innovation practices, making it more relevant than SST). Additionally, it considers non-linearity of innovation (making it more relevant than Diffusion of Innovation). And NPT is widely used in the health and care system analysis and it considers the complexity of the health sector (Gillespie et al., 2018). This gives me another reason for using this approach in that it provides a systematic but flexible tool in collecting and analysing data (May and Finch, 2009).

Despite its benefits, there are also a number of drawbacks in using NPT, with these drawbacks including associated difficulty in coding data and possible overlaps between different constructs. I minimise this risk by using NPT to develop a framework for data collection. In order to do that, the NPT coding framework was used to form the questions to be investigated during data collection. These formed the basis for the process of analysis.

3.6.3 Use of Normalisation Process Theory (NPT) in this research

NPT, which is widely used in health settings e.g. (Gallacher et al., 2011, Elwyn et al., 2008, May et al., 2011, Kennedy et al., 2014, Pope et al., 2013, Murray et al., 2011), enables the researcher to explain actions rather than beliefs. There are four constructs in NPT: Coherence, Cognitive Participation, Collective Action, and Reflexive Monitoring (May et al., 2009).

- Coherence: the sense-making action of individuals or collectives when they are faced with operationalising of a new technology.
- Cognitive Participation: the relational work of people in building and sustaining a community of practice around a new technology.
- Collective Action: the operational work that people do to enact a new technology.
- Reflexive Monitoring: the actions in relation to appraisal by people in assessing and understanding the ways that a new technology (or possibly its resulting practices) affects them and others around them.

Table 3-2 represents the four constituent NPT constructs (May and Finch, 2009) and the relating questions in my study. In Table 3-3, I expand on this by highlighting the mechanisms, components and investments involved in the implementation process (May and Finch, 2009), clearly showing how each construct is explored by developing a list of questions to be examined during the course of the interviews. The list of questions identified in Table 3-3 aggregate to provide a basis for answering my research questions. For instance, in the case of communal appraisal, I explore how SM influences coordination between organisations and individuals and how it enables people to build groups that are effective in service delivery.

	Coherence (sense-making work)	Cognitive participation (engagement/buy-in work)	Collective action (enacting work)	Reflexive Monitoring (appraisal work)
Defin	What is the work?	Relational work Who does the work?	Operational work How does the work get done?	How is the work understood?
Questio	What gets done with SM in co-production? What gets done with other mechanisms?	How does SM facilitate participation within the intervention?	If an actor did not have SM, what would happen to his or her work (in terms of quality of service delivery)?	Does SM allow participants to reflect on the work they have done?

Table 3-2- Representation of the four constituent NPT constructs (Source: May and Finch (2009))

	Differentiation	Enrolment	Skill-Set Workability Interactional Workability	Reconfiguration
Definition	An important element of sense-making work is to understand how a set of practices and their objects are different from each other.	When a set of practices is new or modified, a core problem relates to the question of whether or not key participants are working to drive them forward.	This refers to the interactional work that people do with each other, with artefacts, and with other elements of a set of practices when they seek to operationalise them in everyday settings.	Appraisal work by individuals or groups may lead to attempts to redefine procedures or modify practices, and even to change the shape of a new technology itself.
Questions	What gets done in SM? What gets done in other ways? What are the overlaps?	Can actors articulate the benefits of SM?	What do the users communicate through SM? To what extent does SM support co-productive work?	Do third party or charity organisations reflect on their activities on SM to develop new services through the use of SM with co-production? Does reflection on SM contribute to redesign?
	Communal Specification	Activation	Contextual Integration Relational Integration	Communal Appraisal
Definition	Sense-making relies on people working together to build a shared understanding of the aims, objectives, and expected benefits of a set of practices.	Participants may need to organise or reorganise themselves and others in order to collectively contribute to the work involved in new practices. This is complex work that may involve rethinking individual and group relationships between people and things.	This refers to the knowledge work that people do to build accountability and maintain confidence in a set of practices and in each other as they use them.	Participants work together, sometimes in formal collaborative, sometimes in informal groups to evaluate the worth of a set of practices. They may use many different means to do this, drawing on a variety of experiential and systematised information.
Questions	Communal Specification: How does SM contribute to the work? Do people agree with this as an account of the collaboration?	Activation: Can actors articulate how their work will change? Are they positive about this?	Contextual Integration and Relational Integration: when users contribute in SM threads, does this have any influence on the decisions made? How does SM activity become captured and reused?	Communal Appraisal: How does SM influence coordination between the org. and individuals in this context? Does SM let people build groups that are effective in terms of service delivery?

Social Media in Health and Care Co-production

	Communal Specification (2)	Activation (2)	Contextual Integration Relational Integration (2)	Communal Appraisal (2)
Definition	Sense-making has an individual component too. Here, participants in coherence work need to do things that will help them understand their specific tasks and responsibilities around a set of practices. For example, nurses recruiting patients into a trial need to have a strong understanding of the work they must do to secure informed consent from patients, and how they will go about this.	An important component of relational work around participation is the work of ensuring that other participants believe it is right for them to be involved, and that they can make a valid contribution.	This refers to the allocation work that underpins the division of labour that is built up around a set of practices as they are operationalised in the real world.	Participants in a new set of practices also work experientially as individuals to appraise the effects it has on them and the contexts in which they are set. From this work stems actions through which individuals express their personal relationships to new technologies or complex interventions.
Questions	Individual Specification: what does each actor use SM for? How is that different from what other actors do?	Initiation: do actors understand their new activities involving SM and are they happy to conduct them?	Interactional Workability and Skillset Workability: how do responsibilities change?	Individual Appraisal: how do individual carers or service users appraise the effects of the use of SM on them and their environment?
	Meaning (internalisation) 4	Legitimation	Relational Integration Contextual Integration	Systematisation
Definition	Finally, sense-making involves people in work and relates to the understanding the values, benefits and importance of a set of practices.	Once it is underway, participants need to collectively define the actions and procedures needed to sustain a practice and to stay involved.	This refers to the resource work, being the process of managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies and procedures.	Participants in any set of practices may seek to determine how effective and useful it is for them and for others, and this involves the work of collecting information in a variety of ways.
Questions	Meaning (internalisation): what would be lost if SM were not used?	Legitimation: to what extent do actors and organisations believe that the actions involving SM are important to the provision of the service?	Relational Integration and Contextual Integration: how does SM change the resource flow?	Systematisation: how do organisation (third sector or voluntarily) or individual users of SM in this context determine the effectiveness (benefits or risks) or usefulness of SM in this context?

Table 3-3 - NPT coding framework used for qualitative data collection (part 2).

Type	Method	Period	Description	Mapping Across Chapters
Primary	Interviews	March 2015 - December 2015	18 semi-structured interviews (ranging from 20 minutes to 90 minutes) with private professional care companies, voluntary and charity organisations, project managers of different health and care ICT programmes	Chapters 4, 5, 6
	Online document analysis	September 2014 - December 2017	Online activities of organisations and organisationally affiliated interviewees on social media (for health and care purposes)	Chapters 4, 5, 6
			Analysis of online applications such as HealthUnlocked and Jointly	Chapter 6
			Other types of online documents, including those found on organisation/project websites such as eRedbook	Chapters 4, 5, 6
			Online activity of participants of secondary data on social media	Chapters 4, 5
Secondary	Interviews	September 2015 - November 2015	Eight semi-structured telephone interviews with patients, carers, social media admins or project managers collected by ALLIANCE - People Powered Health and Wellbeing (PPHW)	Chapters 4, 5

Table 3-4 - Overview of Data Collection

3.7 Data collection and sampling

I used multiple data collection methods and sources to gather data for this study. This includes the collection of primary data through interviews and the analysis of online documents and activities and the use of secondary data collected in a project around self-management of patients. Table 3-4 presents a summary of data-collection methods for the entire thesis (a detailed view of data collection sources used within each chapter

is presented in the relevant chapter). The use of multiple methods and multiple data sources allowed me to gain insight into individual and organisational uses and experiences, changes to their lives, activities, and outcomes (perceived and actual), and plans and challenges associated with different types of SM and online applications.

3.7.1 Interviews

The interviews formed the primary data-collection method. They enabled me to bring to light the insights of organisations, carers, and patients and the challenges and opportunities they perceived as holding. I conducted (n=18) interviews (about 36 hours) with employees of private professional care companies and voluntary and charity organisations that support carers or support patients in the UK, informal carers and patients.

16 interviews were conducted face-to-face and two were conducted through Skype or telephone. All participants signed the consent form before the start of their interview. All of the interviews were recorded with the agreement of each participant. The interviews ranged in length from 20 minutes to 90 minutes (with an average of 60 minutes). Some interviews (n=2) were conducted in two sessions due to the time constraints of the participants. A full list of interviewees is provided in Table 3-5. I present the interviews used in each chapter separately.

#	Organisation Name	Role in Organisation	Organisation Description
1	Bright Care	Business Manager	Private Profit Carers Co.
2	Bright Care	Care Supervisor	Private Profit Carers Co.
3	MyDex	Edinburgh Branch Manager	Digital Company
4	Vocal	Carer Centre Communications Worker	Support Voluntarily Carer Organisation
5	COPD Specialist	Medical Researcher	COPD Researcher
6	ALLIANCE	Director of Development & Improvement Health	Charity and Intermediary Health and Social Care Scottish Organisation

#	Organisation Name	Role in Organisation	Organisation Description
7	My Diabetes My Way	Software Developer	NHS Scotland & Scottish Diabetes Group
8	Digital Life Sciences	Head of Illumina Scotland	Year Zero (Inc. No-Delay, Good Neighbour and Better Plan) Sub prog of DALLAS
9	UoG/Art	Institute of Design Innovation	Designer - University
10	LiU (two interviews)	Programme Manager	NHS Scotland and digital care company
11	Our Big Box	Co-Founder	Charity
12	Healthunlocked	Co-Founder	Technological health and care company
13	British Lung Foundation (BLF)	Digital and Marketing Manager	Charity and Voluntarily Luong Health and Care organisation
14	Scottish Council for Voluntary Organisations (SCVO)	Programme Manager	Intermediary Scotland's charities, voluntary organisations and social enterprises
15	ALLIANCE – PPHW Project	Development Manager	Charity and Intermediary Health and Social Care Scottish organisation
16	ALLIANCE – Tommy on Tour	Dementia Carers Voices Project Engagement Lead	Informal carer, campaign leader at Charity and Intermediary Health and Social Care Scottish organisation
17	(Sitekit) e-Redbook	Business Development	Developed health app (e-Redbook - Part of DALLAS)
18	ALLIANCE Self-Management	Development Officer	Self-manager programme for health and care people

Table 3-5- Detail of interviewees

Purposive sampling, which is a common technique in the selection of participants in qualitative research, was used in this study. This technique enables the researcher to identify and select individuals and organisations with knowledge, experience or insights into a particular phenomenon (Patton, 2002, Creswell and Clark, 2007). The overall selection criteria for my study related to people who were involved in the

design and development of ICT programs (e.g. the programme manager of professional carer organisations, software designers and support coordinators) in organisations that provide health and care services.

I used the NPT framework to develop a semi-structured interview question guide (Table 3-2 and Table 3-3) to carry out this study. I used an interview guide and tailored the questions to the roles of individuals and the nature of the organisation. The interview guide focused on the services offered by organisations, the types of online applications (particularly SM) used by individuals and organisations, and the challenges and the future possibilities of SM as they were described by participants. The guide was also put together in accordance with the findings of the literature review. Questions were open-ended, and I tried, as a researcher, to be as transparent and reflexive as possible in terms of both discussion and feedback. Participants were promoted to mention any important or highlighted issues, risk, problems and opportunities that had not been identified in the interview guide. This section of data was collected between March and December 2015.

All conducted interviews were transcribed verbatim by hired transcribers. Each transcript was checked for accuracy by me.

3.7.2 Online Document Analysis

To complement the interview data, I followed the online activities of the organisations and individuals within these organisations and their uses of SM for health purposes. These activities included participation in and management of Facebook groups, blogs, Twitter accounts, and other SM applications. I also looked into the websites and online applications of 12 different health and care ICT projects. Details of these sources and their uses are presented in each chapter's methodology section. This data helped me in three different ways. First of all, it helped me to analyse the interview data in connection with the application design, implementation, and use. Secondly, it provided me with further data on the nature of applications and their uses. Finally, it also helped me to track changes over time.

3.7.3 Secondary data

The primary sources of data provided answers to the main research questions around the current uses of SM in health and social care and the reshaping of SM to enable (and reshape) health and care co-production from the perspective of care companies (both private for-profit, and voluntary and charity organisations). However, in order to go beyond the delivery aspects of co-production from the care provider perspective, I complemented the primary data with secondary data, which was already available, in relation to patient and carer perspectives.

This source, which was originally collected by a charity intermediary organisation (working as a link between the government and the private sectors) constituted qualitative data on the uses of SM by patients. The data (n=8) was originally analysed around the uses of SM for self-management of health and care (PPHW, 2016) and published in a report (accessed 2016 – Appendix 3). The data were collected through telephone interviews. The topic guide (presented in Table 3-6) covered the areas of investigation for my research, the main focus of the research being co-production in health and care.

- | |
|--|
| <ul style="list-style-type: none">• The uses of social media for health and care purposes for patients with long term conditions• The key social media used and the reasons for their use• The impact of social media on patients living with long term conditions (managing their condition, empowerment, the advantages of online versus face-to-face activities, etc.)• The concerns of patients and carers and the challenges associated with the use of social media |
|--|

Table 3-6 - Secondary data - the topic guide

Interviews were collected between September and November of 2015. Most of the interviews (n=7) were conducted through telephone. The interviewees were patients with long-term conditions, carers, group/forum administrators or project managers. All interviewees had given their permission and signed off their data to be used for research purposes, including secondary analysis. I also acquired the use of this data

from the project organisation. Table 3-7 presents the interviewee details from the secondary data source. To complement this data, I also conducted further primary data collection on some of the Facebook groups used by participants of the secondary data source. This data collection, which involved analysing the interactions within each group, allowed me to gain a better understanding of the context within which the participants acted. Overall, document analysis enabled me to support and strengthen the research by providing background information, offering helpful contextualisation of the research within its subject or field (Bowen, 2009).

	Name	Information of interviewee	Role
1	Alison	Eczema Outreach Scotland, Closed FBG, Mem 237	Peer Support Project Manager
2	Carreon	Various Closed FBG, Healthunlocked, websites	Patient Ileostomy, IVF
3	Carole	Closed FBG, Addison's Forum, My Diabetes My Way	Patient Addison, diabetic (complicated)
4	Donna	Closed FBG, patientopinion.org.uk, Establish Hope café	Patient and admin
5	Edmund	crohnsandcolitis.org.uk (Forum, Closed FBG) 16k mem, YouTube Channel, Some another Forums, #GetYourBellyOut FBG.	Patient with ulcerative colitis
6	Karen	Forums, colitis the UK Forums	Patient with ulcerative colitis
7	Kirsty	Closed FBG - Crohn's and Colitis the UK, Get Your Belly Out, Young Adults Forum PSC and the PSC group	Carer with colitis conditions
8	Laura	Subarachnoid haemorrhage	Patient

Table 3-7- Summary of secondary data

3.8 Data analysis

The data were coded in NVivo version 11 (QSR International) and thematically analysed for each type of SM. I inductively identified emerging themes surrounding the benefits and challenges of SM in enabling co-production in health and care. Those

that did not fit within the narrative were explored in most detail. I categorised the results based on each research question. I explain this in more detail in chapters 4, 5, and 6.

I read each transcript (from primary and secondary sources mentioned above) and each observation field-note separately and created codes for each case. Findings from each case were then compared to build a categorisation of uses of each type of SM for each type of carer. Thematic analysis, identified by Braun and Clarke (2006) as “[a] method for identifying, analysing and reporting patterns within data” was used to form categories of data.

3.9 Research governance and ethics

This study was granted ethical approval by the School of Informatics within the University of Edinburgh. Consent forms were signed by all respondents. The template of the consent form and information sheet is available in Appendix 2. The identities are protected and are assigned a confidential generic descriptor to ensure anonymity, with all names having been changed. I used the University of Edinburgh’s licence for the NVivo software.

3.10 Quality in qualitative research

Trustworthiness in qualitative research includes the concepts of credibility (the use of appropriate methods to answer the research questions), transferability (the ability to transfer the findings to other contexts), dependability (the ability to repeat research) and confirmability (the extent of the findings being shaped by the researcher) (Lincoln and Guba, 1985).

I have used data source triangulation to increase the credibility of my study (Padgett, 2016, Mays and Pope, 2000, Barbour, 2001, Mason, 2017). The different data collection methods and sources in approaching the same issue from a variety of angles and perspectives and the subsequent achieving of similar conclusions allowed me to obtain a more holistic view of the matters under investigation. In my research, I have collected different types in different contexts (e.g. primary and secondary sources, and interviews and document analysis). Triangulation helped me to complement different sources and overcome the weaknesses of each individual data collection method. For

example, observing the online activities of individuals and organisations and analysing their documents offered insights into actual practices, whilst interviews offered access to the meanings and reasons behind participants' actions.

Transferability assesses the extent to which the research findings are transferable to other contexts (Mays and Pope, 2000, Malterud, 2001). However, it is difficult to generalise from qualitative studies and apply outcomes to different settings (Mason, 2017). To identify the extent of transferability, I have provided clear and transparent information about the research setting and participants. Transparency enables the reader to determine the quality of research (Mays and Pope, 2000, Green and Britten, 1998, Mason, 2017, Barbour, 2001, Malterud, 2001). I have provided a detailed description of the research methods, including the steps of the data collection, and the reasons behind the choices and sampling strategies. I have also presented the results with detailed descriptions to allow the reader to recognise how transferable the findings are in relation to their own setting (Lincoln and Guba, 1985). This thick description of methods and results also ascertains the reliability of findings in terms of whether they are replicable if the same research study were to be carried out again (Erlandson et al., 1993).

Researchers require to acknowledge their involvement through reflexive accounts which involves reflecting on the way their role affects the research process and its outcomes (Saunders, 2011). In the process of using different methods to collect and analyse data, I have kept a reflective diary throughout the research period. My reflective notes included fishbone mapping of options and choices, lessons learnt during the research (and changes made as a result of reflection), relevant discussions with research participants as well as others who are actively working in the field (e.g. academics working in the field, with this allowing me to ensure awareness of the research circumstances and questioning of my assumptions (Plummer, 2001, Finch, 1993)). This reflection process led to a number of changes to the initial plans (e.g. the addition of secondary data sources), strengthening the research outcomes.

Chapter 4 - The Opportunities and Challenges of General (Existing) Social Media for Health and Care Co- production

4.1 Introduction

In this chapter, I discuss the use of (general) SM to support co-production in current health and care situations. I explore the opportunities and challenges in this area.

4.2 Objective

As discussed in the previous chapter, this study investigates the current and possible future for SM as an enabler of co-production in health and care.

I consider a typology of opportunities and restrictions of SM for health and care: existing health and care services bundles with (1) existing or (2) new SM tools; new health and care services bundles with (3) existing or (4) emerging SM tools (Table 4-1). In this chapter, I focus on section (1) “existing health and care services with existing SM tools”. I therefore explore what the current uses (opportunities and challenges) of existing SM and social care are.

Health and Care

		Current Service	Change Services
Social Media	Current App.	Use of current SM in the existing situation (1)	Current SM help to change health and care services (2)
	Redesign	New SM to cater for the current health and care services (3)	New SM with new health and care services (4)

Table 4-1 - Social media and health and care

4.3 Chapter methodology

The appraisal presented here adopts a socio-technical technique (May and Finch, 2009, May et al., 2009), using a mixed methods framework, including multiple methods described in Chapter 3 (interviews and analysis of online activities and online documents) and multiple sources of data, as described below.

4.3.1 Data sources

I use primary and secondary sources of data for this chapter. In terms of primary data collected, as mentioned in chapter (3), I conducted a total of 18 interviews, seven of which serve as sources of data in this chapter. The interviews are conducted with employees of private professional care companies and voluntary and charity organisations that support carers or patients in the UK (presented in Table 4-2). The overarching interview guide focuses on the services offered, the types of online applications used (particularly in relation to SM), the challenges posed and the future possibilities of SM. Purposive sampling was used to select the interviewees in this part of the research. The selection criteria relate to people who were involved in the procurement, design, development and use of ICT programs (e.g. programme manager of professional care companies, software designer, support coordinator, etc.).

Participant	Organisation	Role	Interview	Analysis of Online Presence				Website information
				Twitter	Facebook	Blog	Others	
P1	Bright Care (private profit care company)	Business Manager	X					
P2	Bright Care (private profit care company)	Care Supervisor	X		X			Web 1.0
P3	British Lung Foundation (BLF - charity and voluntarily organisation)	Digital and Marketing Manager	X					
P4	Vocal (charity organisation that supports voluntarily carers)	Carer and Communications Worker	X	X	X	X	YouTube	Web 1.0
P5	Health and Social Care Alliance Scotland (charity organisation)	Director of Development and Improvement	X	X	X	X		Web 1.0
P6	Health and Social Care Alliance Scotland (charity organisation)	Engagement Lead for Voices Project and former informal carer	X	X	X	X		

P7	Scottish Council for Voluntary Organisations (SCVO - voluntary intermediate organisation)	Programme Manager	X	X	X	X		Web 1.0
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Table 4-2- Summary of primary data collection for Chapter 4

To complement this data, I followed the online activities of the organisations and individuals within these organisations and their uses of SM for health purposes. These activities included participation and management of Facebook groups, blogs, Twitter accounts and other SM applications.

In terms of secondary sources of data, as explained in Chapter 3, in order to capture patient and carer perspectives, I used data collected by a charity intermediary organisation through interviews. In this chapter, I use five (out of a total of eight) interviews (the list of participants is shown in Table 4-3). To complement the data and gain a better understanding of their context of SM use, I also followed the online activities of these individuals as they participated in forums, YouTube channels, Facebook groups and other particular websites, as indicated in the table below.

#	Role	Description
P8	Individual patient & admin	Admin and user of forum and closed FBG (16k mem), YouTube channel, FBG.
P9	Individual patient	User of closed FBG, forum, MyDiabetesMyWay
P10	Individual patient & admin	Patient and admin of closed FBG, patientopinion.org.uk, and Establish Hope café
P11	Individual patient & carer	Patient in forum
P12	Individual patient & admin	Admin and user of forum and closed FBG (16k mem), YouTube channel, FBG.

Table 4-3 List of participants from secondary data source used in chapter 4

4.4 Findings

In this study, I focus on three types of care systems using SM for care purposes: carers (informal carers or caregivers), charity and voluntary organisations and professional organisations providing professional care services. I discuss the findings in terms of these three groups.

4.4.1 Professional carers

Professional carers, who are paid to provide care services, rarely use SM for their work. My observations indicated that the main purpose of SM in these organisations is for advertisements or the sharing of information. Carers are generally reluctant to engage in SM activities of the organisations they work for. The organisations too do not want to be connected to their professional carers through their SM sites (e.g. they did not want to be ‘friends’ with their professional carers on their Facebook page) because professional carers tend to work for these organisations for a limited time (e.g. one year or less), and so they have a high turnover and do not want to be involved with them on one to one basis.

“The company has a Facebook page, but we are not interested in this because they don’t want to be connected with carers again on the professional level.” (Professional care manager)

The only type of connection between carers and the organisation they work for is that some line managers (in organisations) appreciate the work of carers through the SM (Facebook). The interviewee emphasised that she found SM to be an effective informal way to praise their carers.

The literature shows that SM reduces the isolation of patients or carers (Mittal et al., 2012, Cornejo et al., 2010). While my findings show similar results, they also show that the SM connection between people is not the solution to all of the relationship-related needs of patients. Patients may need face-to-face (or voice-to-voice) connection with people, rather than interaction through a device.

“[It is] all about relations between people so they need to see a human being..., they need word of mouth, they need good testimony.” (Professional care manager)

Carers and patients believe that contact through SM is good but insufficient; the patients need to be in physical contact with others, including their carers.

“The problem is not loneliness, it’s aloneness. That is the problem, and although my family phones every day to see how well I am, that is not the

same as having human contact. That is the bit that most people are talking about, going to the Internet, it is wonderful... I went on courses, I just did not like it, I like to speak face to face, have a discussion. I went out for coffee when my husband was ill, I took him out every morning, and it was wonderful, the way the girls in the coffee shop, chatting to a human kicked in life, and honestly it is the aloneness that is the problem.” (Carer)

The privacy of data is one of the biggest controversial issues in relation to online activities (Norval, 2012). In SM applications, patients’ information sharing and the safety and privacy of data are important challenges. Professional carers explained that they could not discuss their daily patient stories with others online due to privacy issues. As a result, their use of SM for their daily activities reduced.

“I think there is a risk, personal data issues. I think a lot of people are using online stuff. Still that is a main risk.” (Voluntary care organisation)

Or in another case,

“The general risk is people might be deciding to post a question on Twitter without realising that it is not a private forum, so they might post private information on Twitter, which they might regret later.” (Professional carer)

Another reason that professional carers are reluctant to use SM for their work is that they believe that the usage of these applications depends on the degree of friendship, meaning that they prefer to use SM exclusively in their private life.

“I did not try to use the application because it is up to the level of friendship [...] we do not use it on a kind of business level.” (Professional care manager)

As discussed in Chapter 2, the population of the elderly that uses SM has been increasing more than other age groups (Brenner and Smith, 2013) because digital users are becoming older. For instance, there is a significant increase in the number of 50 to 65 year old users of SM (Pew-Research-Center, 2018). This shows a change of communication methods, which is one of the areas of co-production. However, the professional carers believed that there is still a significant gap between the two

generations in terms of the use and familiarity with these kinds of technologies. This means that, despite the growth, there are still many people who are not using SM, and so they cannot benefit from it.

“There is still the generation who are not so much convinced. The big gap between this generation and the other is a massive gap”. (Professional care manager)

Despite these difficulties, there is one group of people who are very interested in using SM for their work. Professional carers are keen to expand their uses of online applications. However, the organisations do not allow this. So, despite a bottom-up demand for SM, the top-down structure is inhibiting use.

“... my boss is not so keen to push this direction probably, but this is for my own sake. I was desperate to find an application for using on my iPhone and iPad so that it can help me everywhere I go.” (Professional care manager)

In summary, despite the interest of professional carers in using SM for their work, they rarely use it. The use of SM depends on the degree of friendship between different professional carers. However, professional carers believe that there is big gap between different generations in their use of SM. SM can reduce the isolation of patients and carers, but it is insufficient as a total solution, and they still need face-to-face interactions. The safety and privacy of data is still a challenge in this area.

4.4.2 Charity and voluntary organisations

In most cases, I observed that in charities and voluntary organisations, SM is used for specific collaborations with other organisations through the sharing of information or the advertisement of events, campaign or fundraising. I observed some professional health-related SM, such as healthunlocked.com, which are used by organisations to share information or help other organisations to broadcast various items of information.

Despite the general belief that use of SM can reduce the costs and use of resources (Chou et al., 2013), charity and voluntary organisations do not use SM widely in their

daily activities. For instance, they do not make private groups for discussions with their users. The main reason is said to be the lack of resources, or a lack of a clear approach or budget for managing and maintaining information on these sites. For example, an organisation using a blog for their daily work claimed that managing SM requires a lot of new resources.

“I suppose the thing is with the forum, it is very much a case of, it is a resource for us to run this consistently. It does take time. Somebody does need to be keeping an eye on this every day so that does present problems, for example when we are closed over Christmas, what happens then. I mean to be honest with you I think the people were lucky in a sense that the people who use our forum tend to be respectful and manage each other, manage the problems themselves. But there have occasionally been problems where people have not always been completely respectful of each other. But they are few and far between thankfully.” (Voluntary organisation)

Charity and voluntary organisations mainly use general SM for broadcasting or advertisement.

“We use SM to broadcast information to people, so every day we get something on Facebook, and Twitter. We might share information from other organisations that is relevant to carers.” (Voluntary care organisation)

SM are also used for fundraising or campaigning in these organisations.

“We use Twitter, Facebook, everything for fundraising [and] email marketing.” (Voluntary care organisation)

In some cases, it is used to coordinate the activities of different organisations. This kind of collaboration can be considered an instance of co-delivery of resources.

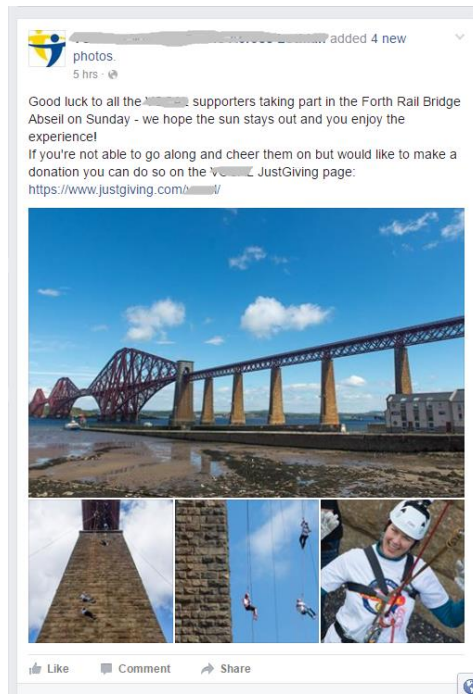


Figure 4-1- Use Facebook to invite people to an event

“... tends to be more around campaigning work, where, for example, we are campaigning around tobacco control. There is Cancer Research, the British Heart Foundation, which have joined together to try to maximise influence on SM, and off SM as well. But also, we work with much smaller charities on the other scale called (...) where they would run a Facebook page, but we would also offer support, you know, that kind of thing. We also work very closely with the NHS but that tends to be locally as well.”
(Voluntary organisation)

In general, I observed that SM is particularly useful in relation to helping to facilitate coordination and collaboration between people and organisations, meaning that co-delivery is taking place through SM between people or organisations (Figure 4-1 and Figure 4-2).



Figure 4-2- Use Twitter to invite people to an event

Similarly, in relation to coordination, a new service that is introduced by a charity organisation that works through SM is the matching of people with the same conditions for more collaboration.

“This is a scheme which we are running which we are actually phasing out. But we are running what we call a Pen Pal scheme and that is where somebody wants to talk to somebody else with a similar condition, we would match them up with somebody else they could talk to. That has been going for about ten years and what we will tend to do is they will email in with their contact details and we will share, we will match the two people together.” (Voluntary organisation)

The observation of websites associated with the voluntary or charity organisations indicates that they use mostly web 1.0 and the users make limited contributions to their online site. In some organisations, there is limited use of blogs in their website for sharing stories of their patients or carers. This is an effective way of sharing the user experience and allowing for motivation to be more active in this space. However, there are concerns about problems such as the giving of medical advice by patients and carers that may not be correct. So, the organisations have to introduce policies with regard to what can and cannot be shared on the blog.

“Something like the forum, it tends to be you know, people publishing their own information and the forum is going to be a difficult one because it is people posting their own experiences and that might not be medically right. Their experience might not match up with what a healthcare professional says, but I suppose our way of mitigating that is that we have a clear policy about what we allow on the web community on the Forum and it tends to self-manage quite well.” (Voluntary organisation)

So, to avoid sharing ‘bad’ information, charities have to adopt various strategies. Some charities prevent their users (patients or carers) from putting their stories directly on the blog. Instead, they filter the inputs to their blogs by checking them before they are shared. Other charities allow information to be published but monitor (and possibly modify, in the event that a policy is breached) this information subsequently.

“And we only tend to step in and delete stuff if it is wildly inaccurate. Say somebody was trying to promote a miracle cure or if it was more inaccurate as opposed to dishonest one of our nurses might go on there and say did you know X Y Z and just point people in the right direction, right information. For the blog, it is less of an issue because it goes through an editorial process and we would not allow anyone to post on the blog. They would have to go through the process first.” (Voluntary organisation)

A set of problems faced by many organisations can be categorised as the ‘problem of access’. The foremost challenge highlighted by charity and volunteer organisations, in terms of access, is that access to the Internet is not available for some of their patients and carers. This is due to a large number of socio-economic factors, such as educational level, income level or geographical location.

“There was a proportion of carers that have no access to the Internet ... [A] percentage of people that cannot access the online resource, for many reasons. They did not have the money, or skills, they did not have the confidence, you know more people are isolated from resources, especially older people. They have not been using tablet devices, you know.” (Voluntary care organisation)

Some also refer to reasons for not accessing the Internet as artificial barriers. These reasons include lack of desire or insufficient encouragement from the younger generations.

“The barriers to using SM or technology is to my mind probably a bit of an artificial barrier because I think there are people who [...] for a number of different reasons do not want to engage or find it hard to engage with information support.” (Voluntary organisation)

“...people that do not have access to the technology [...] I think that depends on the age and not always depending on the economic and social level they are at. But that is not always the case as I think you do get richer people who do not want to use the Internet [...] I think it also depends on, you might have a son or a daughter who is encouraging you to use

technology or you might not. So, I think it really depends on so many factors.” (Voluntary organisation)

The second challenge in terms of access is finding the right groups and accessing them.

“Like to see if we would like to be able to access you know like closed groups and things you have on Facebook. So, we would like to be able to easily search and find what groups there are on Facebook and what groups are going on. Because that is been really difficult at the moment.” (Voluntary organisation)

The third form of the problem of access is finding and accessing the related information. SM is generally seen as a place to build better information for carers and patients (Moorhead et al., 2013). However, a challenge is to find the information that matches the stage of a condition that patients are in or similarities and differences in terms of the treatments that they receive.

“One of the most interesting things that came out of that was understanding where people are in the journey. If you have just been diagnosed with, quite a difficult state of mind. And you just want a very clear user path. A pathway to the information that you need. But if you are say at a later stage in your journey and you want to find out some more information about research and treatments, whatever, you would actually probably have a different pathway through the website. So, it is understanding how to meet those needs and meet different audiences at different times in their journey.” (Voluntary organisation)

Finally, there are yet many issues that cannot be addressed through the use of SM. For instance, SM cannot be helpful for those who have limited literacy.

“...If people had an issue with literacy and the fact is they cannot use technology then that is not going to make a difference. If we give them a printed booklet, that is no good if they have got a problem with literacy so, whether it is the technology or whether it is in print it is the solution

probably is not anything to do with the information itself it is actually to do with a wider societal issue.” (Voluntary organisation)

I argue that, despite the many benefits of SM for charity and volunteer organisations and their carers and patients, there are still many challenges in the use of SM and there are many challenges that cannot be addressed by SM.

In summary, SM can help charity and voluntarily organisation in terms of broadcasting, fundraising and coordination in relation to events, but it is challenging in terms of making effective coordination between patients and carers. The reasons range from the lack of resources, the complexity of information governance, and data privacy.

4.4.3 Carers (informal carers)

In this section, I use the term carer to cover both patients who care for themselves as well as informal carers of patients. Carers use SM for a wide range of activates. Carers are interested in using SM to reduce isolation caused by their care activities. Through SM they connect with other carers or patients with similar conditions. One common form of SM use by carers is blogs where they share experience and care stories.

“... the blog is base of story centre and you can always reflect back at it ...” (Informal carer)

In this situation, SM has potential as a tool for making co-delivery of service to share knowledge and experience and receive feedback from other people with the same condition. Carers use blogs to share stories, ask for support, and to receive emotional support.

“I was scared, and I was lonely, feeling bad [...] So the Blog was my only way of reaching out to people, to try to anyone and tell my story, how I felt in my heart. Also, to find out a bit more help opportunities.” (Informal carer)

In other words, carers can share their feelings or circumstances and build confidence without the intervention of government or other organisations. So SM enables co-service in this situation.

“I could tell people what I felt like in my heart; so, that was one thing, so it helped take away some of my loneliness because I was lonely, even lonelier. So, it gave me an opportunity, when my mum was to go to bed I would write about how I felt that day, what did we fear? Also, to just introduce to other people going through similar experiences, and just uh... professionals, carer people living with dementia. For many reasons but introduce me to people who... from the confines of my own house I have never met, so it opened up a different world to me.” (Informal carer)

Carers believe that, in certain situations, SM can be a solution to their fear of the outside world. In one case, a carer talked about how he became acquainted with SM after he became distanced from the outside world because of his mother’s particular situation.

“I became a full-time carer, my mum could not be left alone. She was very confused and becoming very frail and that turned into a real struggle for us as a family. We became very lonely and scared and isolated from the life we used to know so it starts off with the treatment from friends and family; people who used to visit my mum did not visit so often and people who used to phone her, did not for many different reasons.” (Informal carer)

I observed that the carers and patients receive knowledge and experience from other people with similar conditions or just comments that give them confidence in dealing with problems.

“It helps them know that they are not alone, that they are not the only person going through maybe feeling or you are feeling guilty or sad or scared or alone. [...] When you hear someone else’s that can help you and also it gives them a place to share, give stuff that is new [...] [it] gives them a place to keep sharing their stories.” (Informal carer)

Different SM can be helpful in different situations. The involvement of carers in blogs is seen as a long-term investment. However, they also use SM for short-term and quick responses. For instance, to ask questions they use micro-blogging (Twitter). It is seen as a convenient platform, with a lot of professional individuals online.

“I think Twitter is about more what is happening right now [...] Twitter more than the blog, I think Twitter is more a faster engagement whereas the Blog is slow.” (Informal carer)

Despite its benefits, carers and patients also faced challenges in using SM. I have grouped the first set of challenges as “creating posts on SM”. The first challenge in this set is to allow carers or patients to begin using SM who have never used it before. In the previous section, I mentioned that there is a noticeable gap between the young generation who are familiar with SM and the older generation who have difficulties in relation to using SM. The main barriers for carers in the use of SM is self-confidence. For instance, carers have a fear in relation to starting to write blogs.

“Writing was one of my biggest challenges... Well, I think that was my main challenge at first was really my self-confidence in myself but once people started, nobody ever...nobody said “Oh your punctuation is terrible” or “Your grammar is not very good” and I realised that was not the most important, that the most important was telling people how you felt and listening to how other people felt. So, once I got over that, I accepted it and other people accepted it; that is how I was writing and that is how I felt and even if it was a bit messy, I did not know because it was about your story ... because it was from a personal, coming from a personal space.” (Informal carer)

Another issue in this set of challenges relates to setting up SM (e.g. blog or forums). The difficulty or lack of knowledge on how to configure the SM sometimes reduces the individual’s motivation or self-confidence in relation to beginning to use the SM.

“I found that I did not know if I could set it or knew what to do. Someone helped me with the initial part.” (Informal carer)

I group the second set of challenges into ‘the response’ to what is shared on SM. For instance, there is the possibility of conflicting feelings, a lack of understanding or even disagreement on the stories shared on SM. This can make carers and patients disappointed.

“Everybody may agree with how you feel, some people might not understand how you feel and eh, I suppose...I think it is an important space. Well, it is just how you feel, so I think different things. [...] My own blog is more of how I feel. [...] it is how I feel about my love for my mum when I was caring for her. It is how I feel about how I felt when I was doing it, so reactions to that can be quite a challenge.” (Informal carer)

This can happen as some users of SM, only read (or understood) part of a whole story and responded controversially without having a complete knowledge of the situation. This in turn can upset those who had shared their stories.

“Sometimes, I think someone jumps in. It is a bit seen on Facebook, so some people would read the first line or something, they will not read the whole story and some people just like to jump into things just because they like to jump in. And when you get used to certain people who just look for ways to pick on you whether it is right or wrong, they are just looking for a space to be controversial.” (Informal carer)

“I found Facebook sometimes a little bit distressing because people would comment on things they really did not know much about.” (Informal carer)

In brief, a wide range of carers use SM for their activities. They use SM for social support, health communications, reduction of isolation, knowledge and experience sharing, receiving feedback, sharing their feelings, and receiving emotional support. Different SM can be helpful in different situations. I defined some groups of challenges, such as challenges in relation to the creation of content, and challenges in relation to responding to or receiving other responses. Overall, SM helps with co-delivery of services in these areas. However, it is more challenging in terms of coordination and co-producing care, which is the reason that there is a lack of activity of professionals in this area. There is also the risk of generation and distribution of folk-knowledge rather than scientific knowledge amongst individuals.

4.5 Discussion

Many scholars have reported on the advantages of SM for health and care services. They show that SM improves health communication by widening the access to health

information published by different groups of people (Moorhead et al., 2013, Chou et al., 2009b, Kontos et al., 2010b, Scandfeld et al., 2010). Studies also highlight the extent of emotional and social support offered by SM to the public (Carroll et al., 2017, Moorhead et al., 2013, Lupianez-Villanueva et al., 2009, Ahmed et al., 2010, Colineau and Paris, 2010, Farmer et al., 2009, Moen et al., 2009, Nordqvist et al., 2009, O'Grady et al., 2012, Selby et al., 2010, Setoyama et al., 2011, Van Uden-Kraan et al., 2011) and patients (Beard et al., 2009, Carroll et al., 2017, Frost and Massagli, 2008, Gajaria et al., 2011, Greene et al., 2011, Hwang et al., 2010, Liang and Scammon, 2011, Moen et al., 2009, Nordfeldt et al., 2010, Nordqvist et al., 2009, O'Grady et al., 2012, Scandfeld et al., 2010, Takahashi et al., 2009, Timpka et al., 2008, Moorhead et al., 2013, O'Connor et al., 2016). My findings confirm many of these benefits, but I have a specific focus on the delivery of health and care to the older population. This particular lens has enabled me to identify the benefits as well as the particular challenges faced by elderly patients, their carers (formal and informal), and voluntary organisations involved in this sector.

In this chapter, I present the data from the perspective of three groups of SM users: 1) professionals and professional organisations; 2) charities and voluntary organisations, and 3) informal carers. Each of these groups use SM in a variety of ways. For instance, professionals and professional organisations use SM for the purposes of formal information sharing and advertisement as well as the development of informal links between professionals. However, these uses can be challenging or can lead to the creation and spread of new challenges. SM is said to reduce the cost of public health communications (Chew and Eysenbach, 2010, Jennings et al., 2009, Scandfeld et al., 2010, Scotch et al., 2008, Signorini et al., 2011, Weitzman et al., 2011). Although my research also points to possible cost reductions in some areas, I have also found that SM can lead to the creation of new expenses for charity and volunteer organisations in terms of controlling the content shared on these applications. My findings show that many charity and volunteer organisations do not have explicit plans for using SM other than for advertisement and information sharing. These organisations face two sets of main challenges. First, there are concerns around the monitoring of the contents shared on SM and the costs involved in this (including bad information and too much reliance on shared data). The dynamic nature of SM, the two-way communication (which tends

to be unregulated), and the various inconsistent forms of information sharing can affect the quality of data available on SM (Adams, 2010b, Adams, 2010a, Clauson et al., 2008, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010, Moorhead et al., 2013). Charity and voluntary organisations, therefore, are concerned about the possibility of distribution of ‘bad information’. The risk of such information is that sometimes it can drive out beneficial and correct information (Cotter (2006) or users may not check for its accuracy (Galeotti and Goyal (2010) and rely on it without sufficient knowledge. To overcome these issues, organisations implement various methods to monitor the contents. Some data are controlled by the organisations (which is costly) and some are controlled through means of co-production by the members of the forums or the readers and writers associated with the blogs (self/peer-monitoring). The second set of challenges faced by charity and volunteer organisations is known as the problem of access, which pertains to their patients access to the Internet, to the right groups, and to related information. Despite these challenges, some organisations have begun to create new services, such as using SM for connecting patients and carers with similar conditions and needs.

There is a large body of literature that shows that SM reduces isolation (Farkas et al., 2010). However, professional carers believe that SM cannot replace all face-to-face connections. Interestingly, professional carers and informal carers have two very different views of SM in terms of their own use. Professional carers rarely use SM, as they believe that SM is for friendly relationships rather than work. They are very much concerned about the privacy of data they can share on care activities. On the other hand, informal carers use SM for a wide range of activities and are much less worried about data privacy. They use SM to share experience and knowledge, receive emotional and social support, and overcome isolation caused by their care activities. However, despite this desire to become involved in the activities, they face numerous challenges, such as a lack of self-confidence or concerns of not being understood or receiving negative reactions.

In summary, in this chapter, I show that each use (and benefit) may link to one or more challenge(s). For instance, whilst there are many opportunities in the use of SM for

sharing user experiences by charity and voluntary organisations, the lack of resources can lead to non- or low-use of SM in order to mitigate the risk pertaining to privacy issues, which may be caused by sharing of patient/carer information. Therefore, although I do not claim that the findings of this chapter constitute a comprehensive list of uses and challenges, I argue that uses and challenges must be studied and understood simultaneously from the perspective of different stakeholders. Parameters for new social media

We need to bring together these characteristics to cater for the needs and concerns of patients and carers in order to coproduce health and care. The particular specifications of existing SM that we need to keep for new applications to cater for the care of elderly patients are:

- The privacy of closed groups and forums while providing accessibility and equality
- The speed and diversity of Twitter
- The sharing of experience on blogs for making knowledge accessible
- The promotion of events and health information quickly over a large population
- The bringing together of carers, professionals and patients
- The encouragement of mutual support

4.6 Conclusion

Existing SM (in particular, Twitter, FB, and blogs) are currently used to improve the coordination of activities and resource use, which in turn enables co-production. I discuss three main actors playing an important role in the health and care system in the UK. These groups make different uses of SM: 1) Professional carers rarely use SM for their care activities; 2) Voluntary organisations, such as charities, use SM for certain activities, such as fundraising, campaigning, and information dissemination; 3) Informal carers use SM more than others in their daily health and care activities, for the sharing of knowledge, experience, and mental support. There are also current challenges in the use of SM, such as low levels of skill, awareness, and literacy, high

setup and control costs, accessing online resources (the ‘problem of access’), and security and confidentiality concerns. Moreover, current SM does not cater to all the needs of elderly people and their carers. There is still a wide gap between different generations of carers and patients who use SM. However, gradually, SM use is growing amongst the older population. Therefore, new functionalities aimed at this particular group require to be designed to better coproduce health and care and manage the needs of elderly people.

I argue that there are a wide range of opportunities in broadening the current uses of SM for organisations and individuals who provide care for the elderly population. Further work is needed to establish the new services (e.g. workforce coordination and cooperative organisations) that can be offered through use of existing SM. Moreover, there is a need to explore the possibility of designing new SM (as a means of overcoming some of the challenges introduced by existing SMs) to cater for the existing needs and new services required. Finally, further investigation is required in relation to the carers and organisations that do not use SM in their health and care activities.

Chapter 5 - How Can Social Media Lead to Co-production (Co-Delivery) of New Services for Elderly Population?

5.1 Introduction

In the previous chapter (Chapter 4) I discussed the first section of this study (area 1 in Table 5-1): current situation of health and care services with existing SM tools. This chapter (Chapter 5), is focused on the second area: How does current SM help to change or develop new health and care services.

The aim of this chapter is to investigate the current and possible future for SM (e.g. private FBGs, Forums, Twitter, and Blogging) as an enabler of co-production in health and care. In order to do this, I use the four underlying principles of co-production (equality, diversity, accessibility, and reciprocity) to examine uses (and challenges) of SM. In other words, I assess how existing SM acts as an intervention during the reshaping of health and social care in the UK by enabling co-production (in particular co-services).

Health and Care

		Current Service	Change Services
		Social Media	Current App.
Redesign	New SM to cater for the current health and care services (3)		New SM with new health and care services (4)

Table 5-1- Social media and health and care

5.2 Chapter methodology

My appraisal adopts a socio-technical technique, (May and Finch, 2009, May et al., 2009) using a mixed methods framework including multiple methods as described in Chapter 3 and multiple sources of data as described below.

5.2.1 Data sources

In this Chapter, I use primary and secondary sources of data. The primary sources of data were obtained through interviews and analysis of online activities and online documents. Out of 18 interviews conducted for this thesis, I have used five interviews and following and analysing their associated online documents and online activities (e.g. use of Facebook, Twitting activities, publishing on YouTube Channel, and etc.) to analyse data for this Chapter. Table 5-2 summarises the primary data sources for this chapter.

#	Organisation	Role	Interview	Online Document analysis			
				Twitter	Facebook	Blog	Others
P1	MyDiabetesMyWay (NHS Scotland)	Software Developer	X	X	X		Web 1.0
P2	SCVO (Voluntary intermediate organisation)	Programme Manager	X	X	X		LinkedIn, Web
P3	Health and Social Care Alliance Scotland (Charity and Intermediary)	Director of Development & Improvement Health	X	X	X	X	Web
P4	Health and Social Care Alliance Scotland (Charity and Intermediary-Self-Manager programme)	Development Officer	X	X	X	X	YouTube, Web
P5	Health and Social Care Alliance Scotland (Charity and Intermediary-People Powered Health and Wellbeing-PPHW)	Development Manager	X	X			YouTube, Web

Table 5-2 - Summary of primary data sources for Chapter 5

In terms of secondary data, to capture patient and carer perspectives, I used eight interview data collected by a charity intermediary organisation through interviews (details of interviews provided in Chapter 3). The details of the interviewees are shown in Table 5-3. To complement data and gain a better understanding of their context of SM use, I also followed the online activities of these individuals as they participated in forums, YouTube channels, Facebook groups and other particular websites as indicated in the Table.

#	Role	Description
P6	Group admin	Peer Support Project Manager & Eczema Outreach Scotland, Closed FBG (Mem 237)
P7	Individual patient	Various closed FBG, forum, Healthunlocked
P8	Individual patient & admin	Admin and user of forum and closed FBG(16k mem), YouTube channel, FBG.
P9	Individual patient	User of closed FBG, forum, MyDiabetesMyWay
P10	Individual patient & admin	Patient and admin of closed FBG, patientopinion.org.uk, and Establish Hope café
P11	Individual patient & carer	Patient in forum
P12	Individual patient	Patient in forums
P13	Individual patient & carer	Carer & Patient in closed FBG

Table 5-3 - Summary of secondary data sources for Chapter 5

5.3 Results

Our findings show that overall existing SM helps support the four principles that underpin co-production: equality, diversity, accessibility, and reciprocity and influence the informal care sector to become more efficient. Below I explain how each principle of co-production can be enabled by existing SM. While appreciating the benefits I also found tensions caused by use of SM as well as challenges that inhibit use of SM for co-production.

5.3.1 Social media enables equality through sharing experience of users as valued assets

To enable equality, individuals need to have the same status within a group and the group needs to recognise the value of the contribution of all individuals. Some types of SM (in particular FBGs - Private Facebook Groups)) seem to allow recognition of skills and abilities of all members within a group.

FBG are widely used by people who wanted to be connected to each other in a secure and closed manner. Participation in these groups needed to be approved by the administrator(s) based on whether individuals are patients or carers of a person with a particular condition. Therefore, those who are members of these groups held experiences, skills, or abilities in dealing with the condition. This knowledge is

recognised by others as an asset that can be shared leading to a sense of being valued by others.

“My knowledge is useful for others and their experience is valuable for me. We talk about our condition and liaising with each other and find ways to deal with issues...one particular case was when I had an issue in using my glucose meter and I found I was doing it wrong, I could've waited to see my GP, but got the answer in the group” (Patient and carer)

These experiences and skills either facilitated knowledge exchange or provide emotional support, which in either cases are seen as important to the group members. There are clear considerations of empowerment when people feel that their knowledge and skills are contributing to a change in the world. Whilst many positive consequences exist, we also need to be aware of the issues that may arise from this knowledge sharing and empowerment. These issues include the extent to which knowledge leads on to changes in the productivity of the health and care system (and possible lack of applicability of knowledge for some members of the group), and the means to prevent inaccurate or harmful information from propagating through the network. In similar terms, health and care professionals express concern over the unregulated transfer of experience through SM, which leads to a need for filtering and integration of information in such groups.

In many cases the administrators of the groups also have the same condition as other members (or are carers of people with the same condition). Having the condition meant that they are also equally concerned about the surrounding issues and had dealt with them for a considerable time. Thus, on one hand they brought comparable assets to the group and on the other hand, they are equal in terms of status and position.

“with a closed group, you could have a moderator or an admin who works with that condition, so... they are going to actually facilitate the whole group, and without their, service provision, that group wouldn't exist, and often the closed groups are not run by charities, they might just have been set up originally by someone who has had that particular experience, and

they feel that there is a community for them of people in their situation out there, so they set it up themselves” (Patient)

As a result, whilst the members of these groups appreciate the equality of status, a new tension is created. Patients and carers acquire a considerable knowledge that can stand alongside health professionals; however, by no means are they equal in status or position to them. This in turn can lead to conflicts between the two groups.

This equality in terms of condition and experience remove the culture of “them and us” (McLean and McLean, 2009). This in turn, led to higher levels of support between all members (including administrators).

“they are volunteers who live with the condition, not employees of any organisation” (Patient)

This is achieved by closed-ness of the group (to ensure participants have similar levels of experience). However, this closed-ness can lead to tensions in terms of accessibility and diversity elements (discussed in the next section).

This equality in FBGs empower users to talk openly about their professional care practices and even discuss and find ways to approach professional carers (e.g. GPs, NHS consultants, etc.).

“I definitely feel more in control too. For example, I was fobbed off a couple of years ago when asking a doctor for vagifem and he said to use KY Jelly. The ladies here gave me the confidence to go back to my usual GP and ask assertively for the vagifem I knew I needed. He agreed that vagifem was a good idea and has prescribed it for me ever since.” (Patient)

So, in general FBGs (and Forums) generated a sense of community which facilitated equality amongst its users. However, there are times that things do not go as smoothly. Some members are aggressive about the stance they took on issues which can lead to disagreement, or in more extreme cases abandoning of the group.

“Some people are militant when talking about their stance pro/anti surgery for Colitis and Crohns. They’ll really push their ideas on people and be

very hard to talk to. You might have one person claiming to have the perfect solution to your problems: 'Just cut out dairy!' Or someone else claiming that surgery or medication is a con by the health professionals. With Colitis and Crohns there are such extremes of symptoms and illness and a lot of people are frequently misdiagnosed due to this.' (Patient)

Moreover, SM let patients form coherent pressure groups and that solidarity can promote equality with professionals by providing support.

There are also several aspects of equality, which are not truly known by SM. For instance, some groups are very homogeneous – they are all patients and they all agree on treatment. The influence of these groups on other stakeholders is not known. Another case is where there are conditions with competing treatments. In this case, competition may arise within the SM groups. When dominant groups emerge, there is uncertainty in promotion of equality.

In summary, FBGs and Forums are widely used by patients and carers with similar conditions to connect to each-others. The knowledge and skill of people are recognised as assets that can be shared. Most of these groups are run by patients or carers, which increases the equality in terms of condition and experience by removing the culture of “them and us”. This equality has empowered users to talk openly. However, there are also particular aspects of equality which are not supported through use of SM.

5.3.2 Social media enables diversity by being inclusive of under-represented groups as well as by connecting diverse groups of people

Diversity is enabled by SM in two ways. Firstly, patients and carers are diverse in terms of characteristics (e.g. literacy) and conditions. These differences can lead to less ability to access and use resources. Inclusiveness means overcoming these diversities and making sure that the people who are less likely to access/use resources, gain the benefit of these resources (and SM provides mechanisms to facilitate access/use). SM supports two aspects of access: 1) by making information available to wider groups, and 2) changing participants' capacity to access information through interaction on the group.

Patients mentioned that the closed nature of some SM in particular the private FBGs and Forums gives them the ability to talk about issues which cannot be discussed face-to-face due to embarrassment about conditions of particular illnesses. This means that some of those who were formerly excluded due to their conditions, can now benefit from these discussions.

“People are more open about their experiences because it’s a closed group. They feel more open than if it was in the public domain.... Online support takes away a lot of the social difficulties of sharing in a group for fear of embarrassment or sounding stupid” (Patient)

And

“On a Forum, you talk about how you really feel, without any of the normal taboos. You can talk about anything.” (Patient and carer)

SM also gives a voice to patients with rare conditions. I observed cases where patients and carers of those with particular rare illnesses got together and formed a community whose voice could be heard by authorities, rather than acting as individuals with no say.

However, although this closeness of Forums is an effective factor in facilitating some of these talks, it also created the challenge of getting into the groups. Thus, this closeness is a drawback as individuals cannot join closed groups without the permission of the administrators.

SM is not able to overcome many of the other barriers. For instance, interviewees highlighted that not everyone can have access to various SM types such as FBGs and Forums. This can be due to limited internet access or low technological literacy.

Another challenge is dealing with the Internet trolls, people who get involved in discussions but start quarrel or upsetting other people in the groups by posting inflammatory and digressive contents, or off-topic message in online communities. I also observed examples of individuals trying to sell drugs or miracle cures for different conditions (Chapter 4). All these types of unwanted involvements, need some type of

control to be avoided. In some cases, this control is achieved through the joint monitoring offered by members of the group.

“... [the group administrators] are volunteers who live with the condition, not employees of any organisation. They ensure that the group’s rules are being followed and keep an eye on what’s being said.” (Patient)

The close nature of FBGs, can help also help this control to a certain extent, by for instance introducing restrictions on topics of discussions, or monitoring and deleting inappropriate contents/members. However, there is a no guarantee and people can still join groups with fake identities and produce undesirable activities.

There is also a movement by some users to move away from closed-groups to more open types of SM, such as micro-blogs (Twitter). Micro-blogs are flat in nature, use hashtag to provide links and follow-ups on topics or to provide a way to monitor trends of subjects. These reasons are potential motives for use of such tools by professionals. So, some types of SM, such as Twitter, acted as an effective place for connection of diverse people in health and care sector including professionals and non-professionals (carer and patients). In comparison to many other SM, a larger number of professionals use Twitter.

“I think generally Twitter has certainly helped us to increase the amount of people that we have on the network. And also, to increase the amount of people that come along to the events. But again, we feel that that’s mostly in that professionals. So, we don’t really think that it’s been helpful in terms of targeting people with long term conditions or carers at the moment.” (Organisation participant)

As Twitter is a rapid and flat SM application, it provides a good space for users to find answers to their questions (without necessarily having to connect directly), getting current information and keeping up-to-date with health news.

“I think twitter been used for exchange of informal information and really really useful information around about research. I found it extremely useful for the work on health literacies So, you get to know people who are

working and developing interesting stuff from health literacy ... twitter is good for following and that keep yourself up to date.” (Organisation participant)

The flat nature of Twitter (no connections needed) also provides a good platform for raising funds or promoting campaigns by organisations and charities. In doing so, organisations use Twitter to promote their activities and keep all users updated.

“so, we’d be very keen to promote our work [on Twitter], so we make sure that they’re linked to, we would be promoting.” (Organisation Participant)

“it’s useful for campaigns as well, so there’s been a lot of really effective health campaigns on Twitter” (Organisation participant)

However, issues such as filtering imposed by the NHS in the use of SM on its premises, leads to limitations in the use of such applications. One participant explained that their organisation set-up a Blog, however its use was constrained due to the firewall introduced by NHS that blocked access to Blogs during daytime for professionals.

“there are a massive [number of] health care staff using social media throughout our day, but the firewall is a big problem” (Organisation participant)

So, whilst SM enables diversity in terms of opening up a space for communication and knowledge sharing of some patients (and carers) with particular conditions, as well as offering a fast and flat platform for various actors (including health professional, social workers and carers) to share news, there are yet many barriers that limit use of SM. As highlighted by the participants, individuals who have internet accessibility issues (due to limited internet access or the inability of some elderly people in using technology) can be excluded from gaining the benefit from SM.

5.3.3 Social media makes groups’ experience accessible

To allow accessibility means everyone should have the same opportunity to participate in activities (receiving knowledge and support) in a suitable manner. By offering various types of platforms (e.g. Blogs, FBGs, and Twitter), SM allows different

individuals to take part in knowledge sharing and communication in a way that suited them best.

“The one thing we found about Twitter, it seems to be very much used by the professionals. We find that most people with long term conditions and carers will use Facebook. Whereas with Twitter, we will seem to target lots of professionals.” (Organisation participant)

SM makes information available in two ways. Firstly, by signposting where it is and providing an accessible platform, and secondly, by enabling more experienced people to help others understand information that otherwise they might not.

SM allows patients to gain access to some of the resources that are shared by professionals. Whilst helping them reach a new layer of information about particular conditions, this do not mean having direct access to knowledge that leveraged their own condition. Therefore, accessibility is enhanced to some extent and for some of the users.

Moreover, accessibility to group experience is enabled for those who have difficulty to gain access to others knowledge otherwise (such as through face-to-face meetings).

“I have quite a bad chest as you can hear, so I can be spending a lot of time on the Forums or groups when I’m shut up in the house.” (Patient)

This accessibility to knowledge from various sources, in turn, empowered users.

“I would say that social media certainly empowers you. By people sharing their experiences, it makes you far more informed. You can find out what kind of treatments are out there and go to appointments armed with information. I also felt more empowered in how I dealt with health professionals if I felt I wasn’t being listened to. In fact, I later lodged a formal complaint to the health board.” (Patient)

“I’ve just had my results in from my test”. GP, I saw him two times, never once told me that these results’ - and they were bad results- The GP missed it.” (Organisation participant)

Moreover, overall SM provides a platform for moving from abstract knowledge to knowledge as it is experienced by patients and carers. This kind of knowledge is made more accessible to other patients and carer who do not hold similar experience. However, at the same time this knowledge could be context-specific (based on the particular status of the patient) which may limit its applicability to others.

Whilst increasing patients' knowledge, this is not necessarily welcomed by all professionals. Some professionals prefer to guide patients' knowledge in certain directions. They believe that this knowledge is partial, and it will either lead to loss of trust or 'interfere' with the course of their treatment (if patients take the advice from other sources rather than their direct health/care professionals). They also believe that this knowledge does not take account of other issues such as limitations in NHS funding. Therefore, it can lead to new conflicts in terms of accessing scarce resources.

Another difficulty mentioned by patients is excessive online accessibility. This refers to the fact that sometimes too much online activity can lead to reduced physical activity. In more extreme cases patients stated that too much focus on the negative comments of others can lead to discontentedness.

"Plus, you've got to watch that you don't get too immersed. You could easily spend all your time on Facebook, or on Forums." (Patient)

"And just talking to people about their illnesses might get you down".
(Patient)

In order to reduce some of the negative effects of SM use, some organisations (such as charities) introduce content and structure 'configurations'. So, at the same time as giving a space to patients/carers to be active in sharing their stories, they would also put a control on what was shared and how it was shared.

"We're generally asking people about their story. And to share our story through our Blog. So, we have like a set guideline for it. We will send people a guideline on how to write a Blog, give them the word limit of the Blog, and what kind of content it's good to have in a Blog." (Organisation participant)

However, such controls are costly to manage as organisation members have to spend time going through each post and modifying them to meet the organisations pre-set framework. To manage this, some organisations use means of co-production by putting people with experience of effective post writings in touch with the newcomers to help them produce content, which is fit for purpose. These mechanisms are adopted organisations to encourage people to share their experience, improves accessibility by structuring participation, and making data much understandable. This mechanism can be seen as “templating” which I will discuss in the next chapter.

To summarise, SM allows different people to take part in knowledge sharing and communication. It means that SM makes experience and skill more accessible for the users in two ways: first of all by providing an easy access platform and secondly by making information more understandable. This accessibility improves patients’ power, but it can lead to too much online presence (leading to new forms of isolation from physical world). This knowledge power is also sometimes not welcome by all professionals.

5.3.4 Social media encourages reciprocity in sharing of knowledge and emotional support

Reciprocity refers to the mutual process of giving and receiving something back. Reciprocity within healthcare involves many different aspects such as: money, knowledge, kinship, power, culture, and many other things (Charon, 2014). Users of SM, in particular FBGs and Forums emphasised that they expected to gain something back from the group. Reciprocity may be direct (members behave in response to other members’ acts) or indirect (cooperation with strangers to gain reputation) (Phelps, 2013). Direct reciprocity can be generally seen in offering knowledge and experience about a topic.

“Using social media is actually pretty empowering. When I was diagnosed, I had to become an expert on the condition and there’s no better source of knowledge for this condition than your own lived experience. I did a lot of personal research: first asking doctors and nurses about it, but the best information comes from the women who live with it.” (Patient and group administrator)

Indirect reciprocity, on the other hand, can be seen in offering emotional support.

“I wouldn’t want to join a group unless I thought that people would be able to empathise and understand what I’m going through. There’s no point in talking to people who don’t understand- they won’t respond appropriately.” (Patient)

The sympathy that come from patients with similar health conditions (rather than paid organisational members) creates added value for its recipients and lead to the creation of a positive relationship.

“The knowledge and information come from the members of the group. It’s the people living with the condition who have the experience of self - managing, not paid employees of a charity who don’t necessarily live with a condition.” (Patient)

Both forms of reciprocity play an important role in keeping the communities going. Therefore, administrators encourage members to participate in talks, to make sure that everyone is receiving something back from the group.

“we ask people to be active participants in the group: to commiserate with each other on a bad day, to be supportive of each other and share knowledge and experiences.” (Patient and group administrator)

Some administrators go further by deleting the members who are not active for a certain period of time.

“People who don’t participate for a more than a couple of months are deleted from the group.” (Patient and group administrator)

This challenge is due to “Free-rider problem”: people benefiting from a good without contributing to the cost for a shared resource (Pasour Jr, 1981). Whilst free riding issue is common in SM, sometimes lack of involvement in discussions is due to lack of knowledge in the topic area or disagreement with the stance taken by other individuals. Therefore, distinguishing between the two (whether someone is a free-rider or just

unknowledgeable) is difficult and as a result the administration of groups is a challenge.

“Even if I don’t comment on posts, I read them so that I may be aware of any issues I may face ... I don’t like the idea of taking HRT (Hormone Replacement Therapy) or any other things like creams and stuff- I prefer the natural route but I do understand now with information posted that each individual has their own opinions on the matter. These opinions and choices are personal to them and I take that on board now because this information is important knowledge.” (Patient)

Whilst reciprocity is important in terms of the overall activities of individuals, the administrators need to be considerate of members with lower volume contributions. In some cases, some patients and carers start their participation as Lurkers, just to get a feeling about the environment or to gain some specific knowledge. It would then take some time for them to reciprocate to the group. Therefore, user engagement can be seen as a gradual phased process. For those people with lower levels of engagement, who would be passive readers, it can begin by encouraging them to read more regularly, then starting to comment and then contributing. The use of SM creates the opportunity to allow for growth of continuous knowledge and emotional conversation of strangers.

5.4 Discussion

5.4.1 Summary of findings

This work indicates how different types of SM enable co-production by supporting its underlying principles: equality, diversity, reciprocity and accessibility. The chapter also offers insights into the challenges involved in use of these SM as an enabler of co-production. Individual users (patients and carers) and organisations providing health care services to elderly people, adopted various kinds of SM to meet their diverse needs. I observed that people contributions evolved as they became more experienced in the use of SM. Table 5-4 summarises the benefits of each type of SM in terms of co-production principles. I also uncovered conflicting views and new competitions which the original framework does not address. I explored these conflicts and competitions in the next Chapters. In general, private FBGs are the most widely

used SM by patients with similar conditions and their carers due to their greatest offerings around 1) equality of members and valuing their experiences as assets; 2) diversity and inclusion of members whose voices are less heard otherwise; 3) accessibility for people from different geographical locations; and 4) reciprocity of knowledge sharing and mutual support. Forums are similar in terms of benefits and use, however, they are mainly sponsored (and administered) by organisations. This allowed for better control of data; however, their formation and access are more challenging. Micro-blogging (e.g. Twitter) is also seen as one of the most highly used SM applications which play very important role in health and care by both professionals (e.g. doctors) and non-professionals (patients). Its ‘flat’ nature allows rapid exchange of information based on users’ interest in topics. Therefore, professionals use is for high level exchange of knowledge, and patients needing information or updates about scientific breakthroughs can easily gain access to information shared by health and care professionals. It is also highly used by those who wish to attract communities of interest or funds or those who wants to provide/receive fast update about news and various topics. Therefore, it serves for a very different purpose to those of FBGs and Forums. Blogging, on the other hand, is used for slow but detailed sharing of stories by people and organisations about their health interests and experiences. I found four affordances of SM that support care for elderly people: knowledge creation and sharing, information dissemination, emotional support, new communication channels. SM afford behaviours that are difficult (or impossible) to achieve before these new tools are used by those involved in the care of elderly people. I further found mechanisms that affect how people engage in the knowledge and support conversation, which may have positive effects or may result in adverse consequences not intended by the participants or other groups involved in care of elderly people. These emergent tensions are the basis for the implications I draw.

In this way, SM offered new modes of communications between not only patients and their carers, but also between them and the professionals. On one hand, professionals gain access to patient stories (blogs, FBGs and Forums) and the details of conditions. This information can be used by doctors for better diagnosis and monitoring of particular patients. On the other hand, patients and carers gain access to new health

and care findings. However, accessing this type of data is not common in all conditions. Some patients, for instance those with cancer or HIV have shown more interest in this type of information.

	Equality	Diversity	Accessibility	Reciprocity
FBGs	Patients with same condition and their carers; Experience and skills seen as asset	Less heard voices are included	Members from diverse geographical locations	Mutual support; knowledge sharing; administration of participation
Forums	Patients with same condition and their carers; Experience and skills seen as asset	Less heard voices are included	Members from diverse geographical locations	Mutual support; knowledge sharing; administration of participation
Micro-blogging		Professionals and non-professionals; No direct connections needed	Re-tweets; provides access to another SM	
Blogging			Accessible by all	Feedback on Blogs

Table 5-4- Social media for co-production

In addition, the joint effort in creation of and monitoring of knowledge contents as well as the self-promoting nature of SM, improve the productivity of health and care organisations by enabling them to publicise information using low cost mediums.

5.4.2 Interpreting findings in the context of the wider literature

The large body of extant studies around the use of SM for health and care focus on who uses these tools (Frisch et al., 2014, Fox, 2011b, Fox and Duggan, 2013, Schaffer et al., 2008, Griffiths et al., 2012) and uses of SM for communication (Moorhead et al., 2013, Egan and Moreno, 2011b, Lord et al., 2011, Rolls et al., 2016). The studies show that SM increases patients’ and carers’ access to health information (Kim et al., 2014, Denecke and Nejd, 2009, Hu and Sundar, 2010, Sanford, 2010, Tian, 2010, Rajagopalan et al., 2011, Nordqvist et al., 2009, Kim and Kwon, 2010, Wicks et al., 2010, Liang and Scammon, 2011, Dieleman and Duncan, 2013). Whilst my study confirms this, I specifically show that SM makes various types of health and care resources visible to meet the needs of elderly patients. These resources include availability of carers (including professionals and non-professionals resources), care

programmes (e.g. outgoings, charity programs, etc.), knowledge about symptoms and cures of different conditions (including diets and drugs), new communication techniques with professionals, and more. I show that by facilitating new modes of dialogue between different actors (i.e. patient-patient, patient-carer, carer-carer, patient-professionals, and patient-health and care organisation), SM enables new, faster and more effective modes of social interactions in which patients become empowered by having access to more resources and information. It means, by providing access to information, knowledge and experience of the other people, patients become empowered in two ways: 1) in dealing with their own condition, and 2) in being able to communicate their cases in a more knowledge-rich way, with their health professionals.

SM offers a wide range of benefits for health communication which can be grouped into increased interaction around general (Adams, 2010b, Frisch et al., 2014) and sensitive information (Colineau and Paris, 2010), better accessibility of information (Chou et al., 2009b, Kontos et al., 2010a, Lariscy et al., 2010, Egan and Moreno, 2011b, Egan and Moreno, 2011a, Frimming et al., 2011, Lord et al., 2011, Ralph et al., 2011, Selkie et al., 2011, Dieleman and Duncan, 2013, Frisch et al., 2014), and emotional support (Farmer et al., 2009, Lupianez-Villanueva et al., 2009, Moen et al., 2009, Nordqvist et al., 2009, Nakayama et al., 2009, Ahmed et al., 2010, Colineau and Paris, 2010, Selby et al., 2010, Setoyama et al., 2011, Van Uden-Kraan et al., 2011, Househ et al., 2014, Grajales III et al., 2014). I used Cahn's co-production framework (Cahn, 2000) to expand the extant findings by showing how such characteristics act as the key principles of co-production. My work shows that SM enables recognition of the experiences and skill of all participants as assets and enables them to engage with the community and become active. My study also expands the existing literature, by showing that the fulfilling of different needs by various SM is influenced by different factors including the speed of knowledge creation and dissemination, the speed of feedback and discussions, the detailed nature of knowledge exchanges, the type of discussion (support versus news versus health knowledge sharing), and the openness and closed-ness of activities. These characteristics help better coordination and communication of knowledge resources between carers and patients.

My findings also point to how the interaction in the social groups and behaviour of particular types of actors change as a result of use of SM. For instance, use of FBGs, increases patients' awareness about their own condition and possible issues around the condition. So, it gives the patients the ability to ask more questions about their conditions when they are interacting with the professionals. Health professionals also become more cautious in responding to patients, because they know that patients now have more information than they did before.

Additionally, my findings show that, different categories of stakeholder, have different emphasis on the effects of SMs. For instance, patients tend to view SM as emotional support and source of complementing knowledge, while clinicians tend to emphasise the information carrying capacity. Carers on the other hand, would like to use SM as for coordinating tool.

There are also limitations in use of SM. Information quality concerns and the lack of reliability of the health information (Adams, 2010a, Farmer et al., 2009, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Kim and Kwon, 2010, Nordqvist et al., 2009, Adams, 2010b, Orizio et al., 2010, Tian, 2010, Friedman et al., 2011, Kukreja et al., 2011, Househ et al., 2014, Oh et al., 2014) are amongst the widely discussed limitations.

Whilst my findings confirm these, I also show that the explication of common resources may lead to new forms of competition and conflicts. In particular, the new knowledge that is obtained by users is not always welcomed by professionals. This could be due to numerous reasons, including lack of validity of all information obtained as well as higher demand for treatments as they become known to patients and carers. Also, due to concerns about information quality and validity, some health and care organisations need to put into place new forms of information monitoring which may be costly.

5.5 Conclusion

SM has gained momentum within the health and care community by: offering significant benefits for patients, carers and even professionals; increasing interaction; providing more readily available and customised information; offering emotional

support; promoting health and care related activities; offering a platform for communication for under-represented individuals; allowing reciprocal sharing; and enhancing the communication between patients, carers, and professionals. All these benefits have the potential to be realised through SM. These benefits facilitate co-production by enhancing equality, diversity, accessibility and reciprocity, and lead to recognition of resources (skills and time), joint creation and monitoring of knowledge, and direct and indirect mutual support. This in turn can lead to resource savings needed to manage the growth in demand from the expanding elderly population. SM allows users to learn from each other (in a less costly manner) and can facilitate communication more effectively (in particular professionals and non-professionals). However, despite these benefits in facilitating co-production, existing SM does not fully enable co-production. There are as yet outstanding issues in arranging the common pool of health and care resources to better enable co-production. Different SM enable co-production (co-delivery) of services for elderly people to varying extents. In particular SM is used distinctly differently by professionals and non-professionals. This can be seen as an opportunity to leverage their benefits in a more productive manner.

Chapter 6 - Developing New Social Media for Health and Care Co- production

6.1 Introduction

In previous chapters (4 and 5), I discussed existing SM used for health and care purposes. In this chapter, I investigate applications developed for health and care purposes that use SM concepts in order to contribute to co-production in the health and care sector.

6.2 Objectives

As discussed in Chapter 3, this study investigates the current state and possible future opportunities for SM as an enabler of co-production in health and care. The typology of opportunities and restrictions of SM for health and care are examined in this study. Existing health and care services bundles with (1) existing or (2) new SM tools. New health and care services bundles with (3) existing or (4) emerging SM tools (Table 6-1). As the new SM or redesigned application can help to existing services or improve or give rise to the new service, these two sections are observed in tandem. So, in this chapter, I focus on areas 3 and 4, relating to the question of how new or redesigned SM help or reshapes current health and care needs or reshapes and the question of how this SM changes health and care services. In other words, I assess how new applications developed for health and care purposes (based on the SM concept) serve to intervene during the reshaping of health and social care in the UK by enabling co-production (particularly co-service).

Health and Care

		Current Service	Change Services
		Social Media	Current App.
Redesign	New SM to cater for the current health and care services (3)		New SM with new health and care services (4)

Table 6-1- Social media and health and care

In order to do this, I introduce a number of new health and care SMS, programmes and applications and the services they offer (new and existing), before discussing my findings with regard to the challenges involved in the uptake and use of these applications.

6.3 The methodology used in this chapter

6.3.1 Material and methodology

My appraisal adopts a socio-technical technique (May and Finch, 2009, May et al., 2009), using a mixed methods framework, including interviews and the analysis of online activities and documents from multiple sources of data.

6.3.2 Data sources

Two main sources of primary data are used in this chapter. First, I use data from six interviews (out of a total of 18 conducted for this study) from five interviewees, as shown in Table 6-2. Purposive sampling is used to select the interviewees for this part of the research. The criteria include participants who are employees of companies or organisations involved in the design and development of health and care specific applications.

#	Organisation Name	Role of Interviewee	Description
P1	Year Zero (by Digital Life Sciences)	Head of Illumina Scotland	Year Zero (inc. No-Delay, Good Neighbour and Better Plan), sub-programme of DALLAS
P2	LiU (two interviews)	Programme Manager	NHS Scotland & Digital care company, Sub-programme of DALLAS
P3	e-Redbook (sub-programme of Year Zero by Sitekit)	Business Developer	Developer of health app (Part of DALLAS)
P4	Our Big Box	Co-founder	Charity
P5	Healthunlocked	Co-founder	Technologic health and care company

Table 6-2 - Summary of interview data collection source for Chapter 6

The second source of primary data was online documents (including websites and applications) associated with 12 different health and care ICT projects (eight of which are sub-projects of two larger DALLAS sub-programmes). The list of projects is shown in

Programme Name	Application Name	Organisation Description	Status in 2019

Year Zero (Sub-programme of DALLAS programme)	A Better Plan	Digital Life Sciences	Stopped working
	Good Neighbours	Digital Life Sciences	Stopped working
	No Delay	Digital Life Sciences	Stopped working
	e-Redbook	Digital Life Sciences – (project done by Sitekit)	Functional
LiU (Sub-programme of DALLAS programme)	Flourish	NHS Scotland & Digital Care	Changed
	Shine	NHS Scotland & Digital Care	Stopped working
	Connect	NHS Scotland & Digital Care	Merged with My Condition My Life
	Discover	NHS Scotland & Digital Care	Merged with ALISS
Independent Apps	Our Big Box	Charity organisation	Stopped working
	Healthunlocked	Technologic health and care company	Functional
	Babylon Health	Private company	Functional
	Jointly	Charity (Carers UK)	Functional

Table 6-3. All of these projects were functional during the initial data-collection period.

Programme Name	Application Name	Organisation Description	Status in 2019
Year Zero (Sub-programme of DALLAS programme)	A Better Plan	Digital Life Sciences	Stopped working
	Good Neighbours	Digital Life Sciences	Stopped working
	No Delay	Digital Life Sciences	Stopped working
	e-Redbook	Digital Life Sciences – (project done by Sitekit)	Functional
LiU (Sub-programme of DALLAS programme)	Flourish	NHS Scotland & Digital Care	Changed
	Shine	NHS Scotland & Digital Care	Stopped working
	Connect	NHS Scotland & Digital Care	Merged with My Condition My Life
	Discover	NHS Scotland & Digital Care	Merged with ALISS
Independent Apps	Our Big Box	Charity organisation	Stopped working
	Healthunlocked	Technologic health and care company	Functional
	Babylon Health	Private company	Functional

	Jointly	Charity (Carers UK)	Functional
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Table 6-3 - Overall of applications investigated in Chapter 6

Year Zero and LiU are sub-programmes of the DALLAS programme (discussed in detail in section 6.4.1), which was run by the government with the aim of developing a health programme through the concept of co-production. They therefore provided data that could cover the aims of areas three and four in the typology of my study (Table 6-1). The DALLAS programme developed applications functioning around health and care services and comprised four sub-programmes. I conducted data collection in relation to LiU and Year Zero (both interviews and documents and application analysis as indicated in Table 6-2 and

Programme Name	Application Name	Organisation Description	Status in 2019
Year Zero (Sub-programme of DALLAS programme)	A Better Plan	Digital Life Sciences	Stopped working
	Good Neighbours	Digital Life Sciences	Stopped working
	No Delay	Digital Life Sciences	Stopped working
	e-Redbook	Digital Life Sciences – (project done by Sitekit)	Functional
LiU (Sub-programme of DALLAS programme)	Flourish	NHS Scotland & Digital Care	Changed
	Shine	NHS Scotland & Digital Care	Stopped working
	Connect	NHS Scotland & Digital Care	Merged with My Condition My Life
	Discover	NHS Scotland & Digital Care	Merged with ALISS
Independent Apps	Our Big Box	Charity organisation	Stopped working
	Healthunlocked	Technologic health and care company	Functional
	Babylon Health	Private company	Functional
	Jointly	Charity (Carers UK)	Functional

Table 6-3). I also collected data from four (non-government funded) independent projects that also drew on the co-production concept.

The documents for these projects were collected from organisations and application websites, blogs, press, and journal articles and other online material. All of these materials were publicly

available. Data collection from these sources was done from mid-2014 to the end of 2017. Some of these applications stopped working later on (as indicated in Table 6-3).

6.4 Investigation on new social media / applications

In this section, I first discuss the specification of each programme, then the benefits and issues of that programme based on the analysed data.

6.4.1 DALLAS programme

The Delivering Assisted Living Lifestyles at Scale programme (DALLAS) was a five year programme that ran between 2012 and 2016. As discussed in Chapter 2, it was funded by Technology Strategy Board and the Scottish Government with the goal of establishing three to five communities of 10k or more people across the UK. It had four sub-programmes that developed applications or websites with the aim of showing how assisted living technologies and services can be used to promote wellbeing, and provide top quality health and care, and enable people to live independently, including the use of a preventative approach. Table 6-4 provides an overview of the DALLAS Sub-programmes. I focus more deeply on the two sub-programmes (Year Zero and LiU) because of their relevance to this research, especially given that they are service-based programmes rather than infrastructure or hardware. Moreover, they used the concept of co-service in providing their services to users.

Name	Users			Coordination Goal
	Profession Carers	Carers	Patients	
Year Zero				
A better plan	X		x	A care planning application designed to help health and care professionals and patients to collaboratively consider and set a range of health, wellbeing and personal goals.
Good Neighbours	X	X		A social networking application allowing users to create circles of support with family members, friends and carers and share or allocate tasks and diaries within an online social support network.
No Delay				An application allowing GPs to prescribe a digital postcard (a personalised package of short videos that explains patients conditions and inform them about available local services via email).
e-Redbook		X		A digital version of the printed Redbook (a Personal Child Health Record) that logs a child's health and care information such as developmental growth and milestones, vaccinations and other information from birth.
LiU				
LiU Portal		X	X	A web-based portal acting as a single access point in relation to the range of services offered by LiU
Flourish		X	X	A suite of interactive tools to support self-management of long-term conditions, experience guides', NHS resources, a home monitoring service and a text messaging service.
Shine		X		An online profiling service to identify individuals' skills and expertise along with encouraging members to help others to share their own skills and talents in their communities.
Connect		X	X	A means for people to remain 'connected' with their friends, family and caregivers via Skype or Cisco Jabber Client video conferencing suite.
Discover	X	X	X	An online portal offering access to information on a range of health and social care products and services available in local communities.
Other Sub-programmes				
More Independent (MI)		X	X	MI offers a wide range of ways to increase independence, some of which are aimed at those with health needs. But it is also suitable for people who are looking ahead and planning the next stage of their lives.
i-focus				An overarching DALLAS community, consisting of three workstreams that aim to bring technical and strategic coherence, cross-sector collaboration, consumer-focused innovation and real commercial scale to the DALLAS programme.

Table 6-4- Overview of DALLAS Programme

6.4.1.1 Year Zero

Year Zero was a three-year programme supported by the Technology Strategy Board and Department of Health as part of the DALLAS project. It was a partnership between four leading NHS providers and five innovative companies bringing together expertise in health and care, design, media and technology to develop new user-centred tools for digital patients and deliver new services around them. The NHS partners were Liverpool Community Health NHS Trust,

NHS Grampian, The Rotherham NHS Foundation Trust and South Warwickshire NHS Foundation Trust. The industry partners were NHS Local, Kameleon, Sitekit and Maverick Television. The aim of Year Zero was the development of a digital tool to transform the relationship between patients and professionals, to establish the same rewards that have been seen in the retail, banking, travel and media sectors. Year Zero was managed and run by Illumina Digital Ltd (Digital Life Scales). Digital Life Sciences was a digital health production company. The vision of this company was to create digital products, environments and experiences that change the relationship between citizens and health professionals. This programme had four sub-projects, as described below.

A Better Plan was a care planning application that was designed to help health and care professionals and patients to collaboratively consider and set a range of health, wellbeing and personal goals.

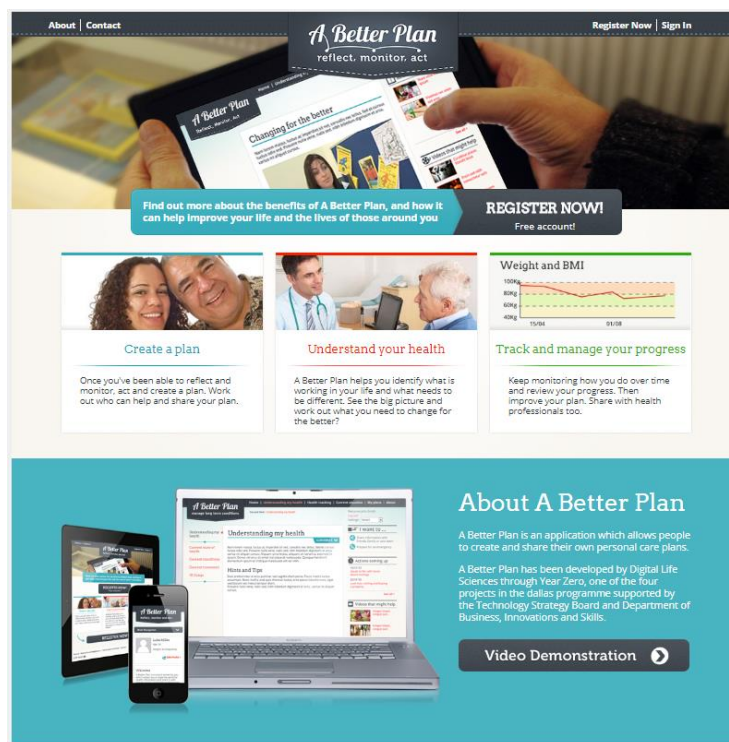


Figure 6-1- Screenshot of a Better plan website

It was an online health journal that patients and carers used to create and manage patients' own personalised life and care plans. It has been used by patients diagnosed with long-term conditions to help them to reflect on their health, find out more about the condition and organise their thoughts so that they can take a more proactive role in discussions with health professionals and informal carers.

Patients and carers kept a set of their health information in one secure place (the cloud). They accessed and updated this information when they needed to and had the option of choosing to share it with others where appropriate.

Specific features of a Better Plan include the following:

- 1) The ability to list conditions and allergies, related medications or treatments
- 2) Log family health history
- 3) The ability to store documents safely in one place, these documents including shared care plans, test results, letters from specialists, scans and any other important documents
- 4) The ability to record and save key home measurements such as blood pressure, blood sugars and weight (such that patients could see any changes over time and share these with their health professional)
- 5) Inclusion of a list of key contacts, such as one's GP, consultants, other health and care providers, family, carers and friends
- 6) The ability to set goals, create plans and share achievements

It also had a library of articles and videos to help patients to learn more about the conditions affecting them.

For the privacy purpose, the company believed that this should be a private service. All clients could control their access to the information and data:

“It's care planning, you're able to share the content you keep in your plan, you can choose to share that with people, not in a sort of an automated Facebook-y type way, it requires a process, but you can, but it's, it is health information, so we believe it should be safe, so what you do is you give access, you choose to give access to certain people, it could be family, it could be health professionals, it could be any number of people, but ultimately it's about the control. It's your data, it's your information and you can choose to share that information with whomever you like.”
(Programme manager)

This website was similar to Jointly (another application discussed below) that provides care services in the UK. This programme has been terminated from the date on which the DALLAS Programme concluded.

The screenshot (Figure 6-1) was taken on 18th November 2016 from the web archive (archived on 22 August 2016).

Good Neighbours was a SNS that allowed patients to create and manage a small network of people who they trusted to help them in relation either to day-to-day tasks or emergencies. The patient assigned tasks, shared details of their information, such as a doctor's number or relevant contact information, messaged members and stored information about their condition.



Figure 6-2- Good Neighbours' website screenshot

It managed a support group of clients. The users formed and owned a network, including individuals such as their friends, family or carers in their online support circle and assigning tasks to them. The 'Good Neighbours' support group could then view clients' online calendars and emergency contacts. Users kept track of who had agreed to do tasks for them. All carers accessed their client's calendar so that they could help them keep track of clients' day-to-day tasks. In this application, users or their neighbours assigned tasks to other neighbours so that

they had a record of what they needed to do for each other. It also helped to keep track of who had asked to help with a task or activity. With the ‘circle of support’, users kept an address book that could be accessed by any of other users.

Clients could also add or view articles and other resources that relate to their condition. They could also add information that they liked to share with their circle. Any member of the network could view the resources at any point, and so this served as a way of keeping track of news or medical advancements.

“Good Neighbours is a secure social networking application that allows users to create circles of support with family members, friends and carers to share and allocate tasks and diaries within an online social support network. Messaging to the individual about tasks they need to complete and/or to the wider care circle that they’ve completed tasks. It also has the functionality of a shared calendar and the ability to share key health and social care information with their online support network.” (Programme manager)

or

“Good Neighbours is effectively a social network for allowing people to care for you, getting help - either you are caring for somebody else or coordinating a circle of care.” (Programme manager)

The difference between this site and the personal health record (PHR) is its simplicity in terms of recording and presenting information:

“Good Neighbours is different, it doesn't sit on a PHR because it's not really information that needs to sit on a PHR, it's just a sort of closed social networking site, and the reason we came up with that, it's quite a simple tool.” (Programme manager)

It was integrated with ‘A Better Plan’, where individuals could reflect, monitor, create and act out a planned daily life. Each user therefore had one single account for both applications.

“So Good Neighbours would be the tool that we would like to see informal carers adopting... to date we haven't really gone out there and marketed it in any concerted way... we will be doing it in the next year as a sort of... as a suite of products... and

primarily you see Good Neighbours when you register for A Better Plan, so you're seeing it as the care, if you like, the person who's asking people to coordinate care around them, but definitely it is a tool that we would like carers, informal carers to be using." (Programme manager)

This programme was terminated after DALLAS Programme ended.

No Delays was a video-on-demand service that enabled people with chronic conditions to access specialist advice and knowledge from their health professional whilst at home or on the move. It could be easy to miss key information during a consultation with a GP or specialist, especially if the diagnosis was a shock, or the explanation involved quite technical medical language. No Delay allowed the GP or the specialist to email patients a personalised video, called a "postcard", containing short videos that explained their condition and diagnosis. The videos also enabled patients to meet members of the local team involved in patients' care, understand the local services available, and hear other patients describe their patients' experiences of living with the condition.

The videos in each Postcard introduced members of the NHS team and explained their role. There were videos of patients describing their experience of living with the condition and the ways in which they have adapted to it. There were also links to support groups and other approved sources, and quizzes that tested the patient's understanding and knowledge of their condition.

It aimed to transform the way in which patients interacted with their GPs and health professionals via:

- a digital platform that clinicians could use to prescribe personalised packages of health and care to patients
- service redesign activities that enabled health teams to integrate digital transactions within new, improved workflows
- high-quality video and text content tailored to the patient's own health needs and designed to improve patient education
- interactive exercises and self-assessments designed to support compliance, self-care activities and transactions
- remote access to self-management services offered in the region

- locally produced video that enabled patients to meet the people who were part of their care pathway
- links with self-management tools that enabled a reduction in outpatient appointments and ongoing self-care

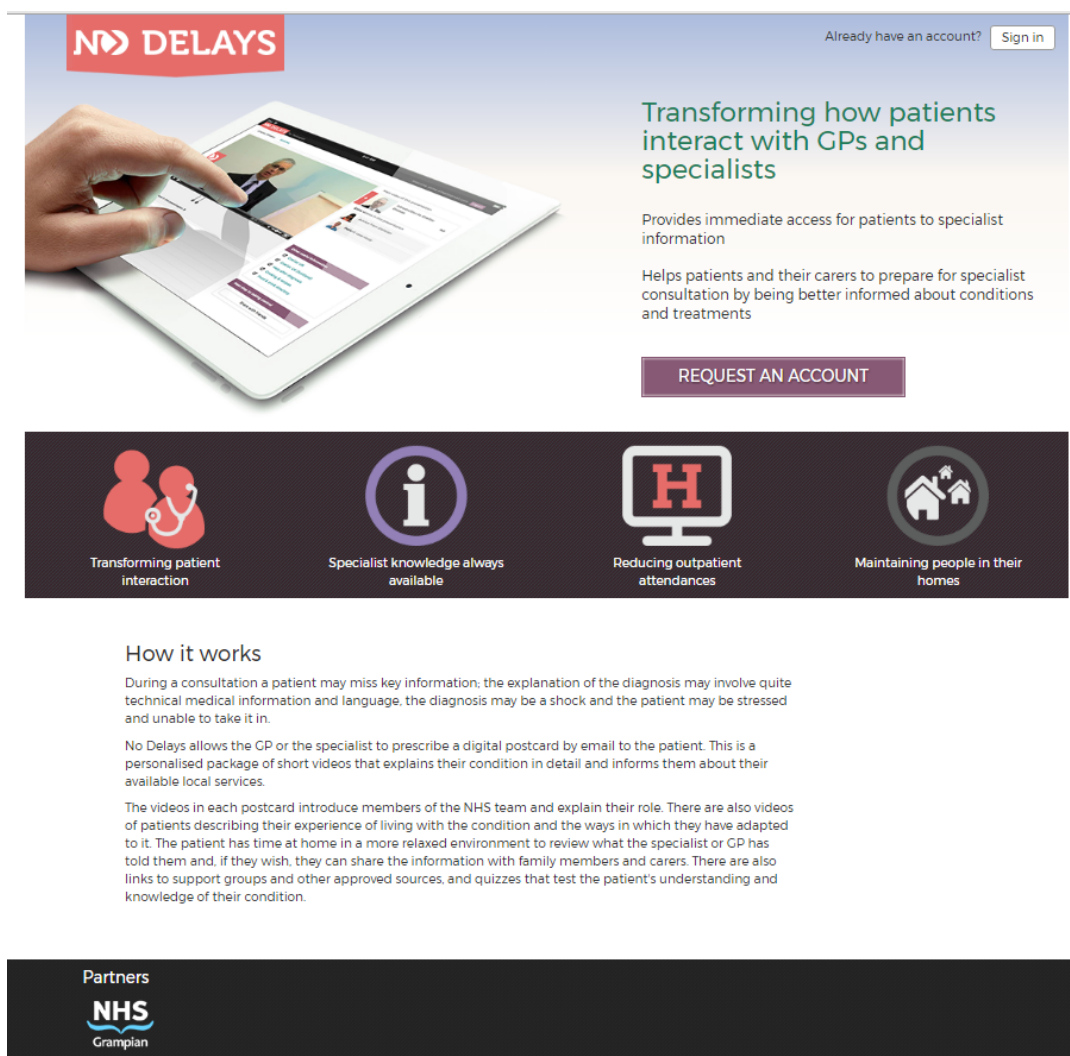


Figure 6-3 – No Delay's website screenshot

The aim of the project was to engage more than 700 clinicians in sending the electronic postcard. This company did not provide any further details on their application. This programme was terminated after the DALLAS Programme ended.

e-Redbook - The PCHR (Personal Child Health Record) - often called the 'Redbook' - is a log/record of a child's health and growth and development that is kept by the child's parent or guardian, with contributions from various health professionals. An Electronic PCHR (ePCHR)

is the same record but kept electronically, facilitating the access of a convenient online service to a child's parent or guardian.

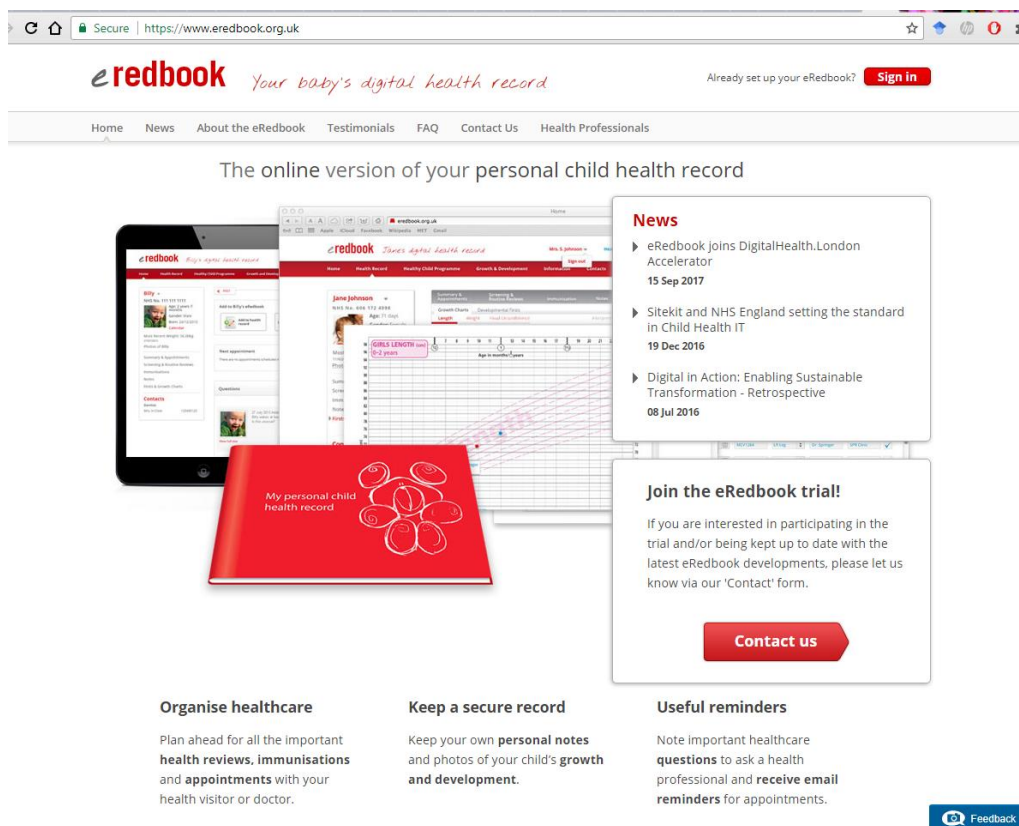


Figure 6-4- e-Redbook's website screenshot

The e-Redbook is the online version of the paper-based record, informally known as the 'Redbook' in the UK. It contains general information of a child's health, growth and development and is held by the parents of the child. This record is updated whenever a newborn child might visit a doctor, midwife, dentist or other health and care professional, or may be updated by the parents of the child in the case of family medical histories, their own observations of their child, and in relation to the updating of address details, etc. It uses Microsoft HealthVault platform to store the associated data. The development has been funded by Microsoft, and the Technology Strategy Board, Sitekit and has received support in the form of economic development funding from the Highlands and Islands Enterprise Board (HIE). The Royal College of Paediatrics and Child Health (RCPCH) is working with Sitekit Labs to evaluate the usability and benefits of the eRedbook prototype. This programme is incorporated into the day-to-day practices across several cities in the UK, in particular in London.

6.4.1.2 Living it Up

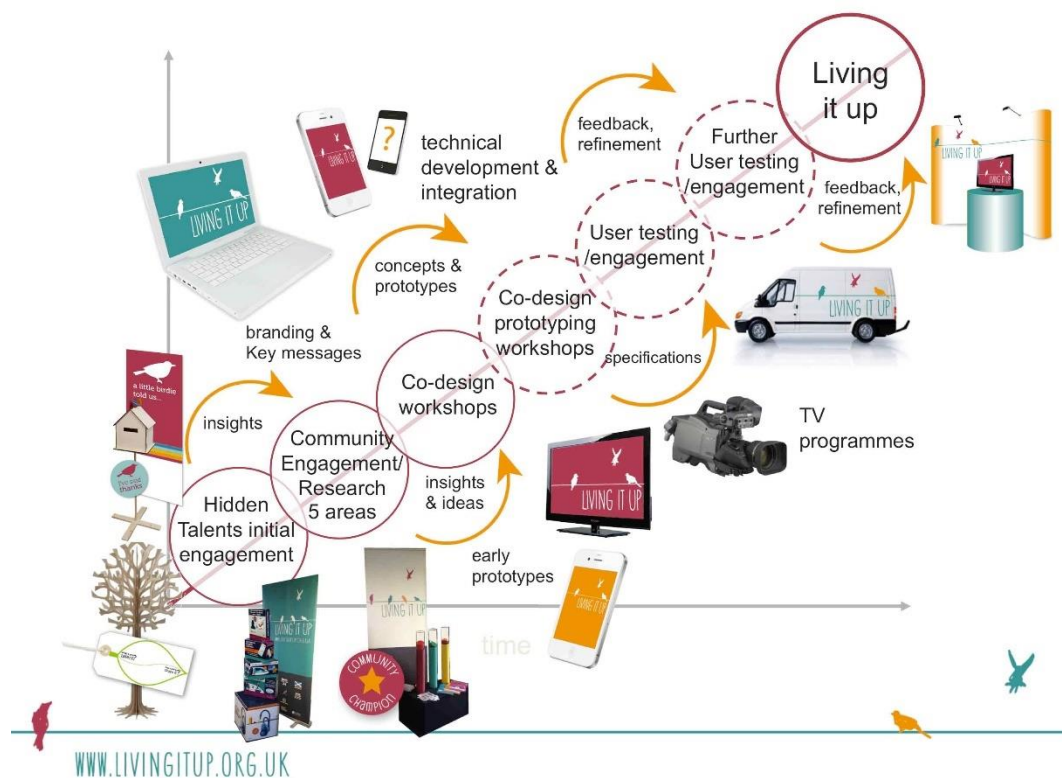


Figure 6-5- First step goal of Living it Up project

Living it Up (LiU) was a Scottish programme (part of the DALLAS project). It focused on developing solutions for citizens to have a better control of their health and wellbeing. This was a three years project which aimed to deliver integrated health, care and wellness services through technologies such as television, mobile phones, games consoles, computers and tablets. It was a health, wellbeing and self-management website for people over the age of 50 who lived with long-term conditions and/or their carers in Scotland. It drew on a co-design and co-production concept by a range of partners in the public, voluntary and public and private sectors. The site hosted everything from localised event information, tools and technology to help with monitoring health, to inspirational videos and support to find new hobbies. It had a person-centred design that supported the management of the high-costs of caring for the elderly population with long-term conditions, through a series of prevention and early intervention initiatives.

It aimed to provide services that matched the lifestyle of the user at their own homes, communities and organisations to support independent lifestyles.

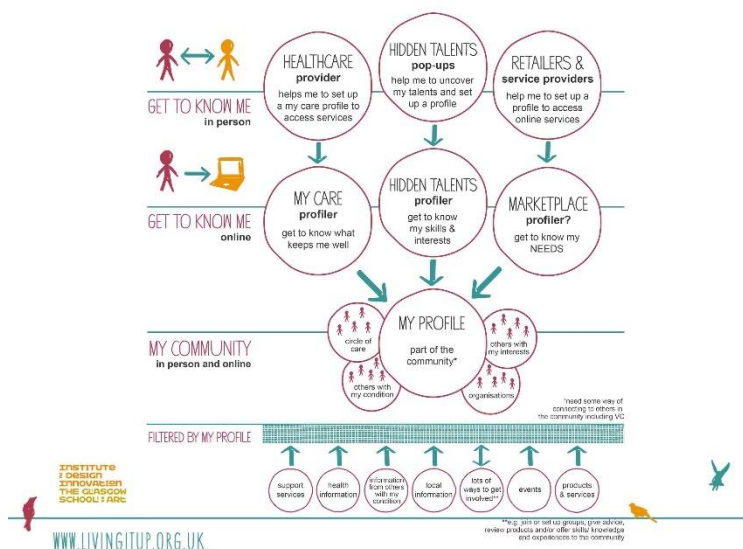


Figure 6-6- Living it Up portal

This programme aimed to provide for 55k people who need this service across Scotland. The idea behind the development of LiU was the creation of an enhanced health and care model:

“The whole idea of what we were to develop was really to think differently about how health and care could be delivered in the future and we had a few key challenges that were highlighted early on. We wanted to co-design a new service with the population at the bottom, so we wanted to do a bottom up approach. We wanted to use familiar technology - so Smart Phones, Smart TV, laptops, tablets - to allow people to have more ownership and more control over their healthcare and wellbeing. And the other key principle was scalability, so how can you actually help or allow a population to co-design a digital service whilst trying to scale it up at the same time. So, scalability for us is up to 55,000 members, so building a community of 55,000.” (Programme manager)

LiU used concepts of SM, in particular forums, to share knowledge on a platform.

“I think Living it Up is developing interactions with their users and you could say that we’re a social media application, I suppose. So for you I suppose social media is that interaction with the user, community and a GP and another user or anybody else. So I think through some of what we’ve developed we’ve either used the mega platforms, the mega social media platforms or we’re building a social media application that allows people to talk to either their clinical or other users.” (Programme manager)

Discover provided health and care information in the local area. It explored health and social care products and services available in local communities. This project was fed by the ALISS programme, sharing information about local services and resources supporting health and wellbeing. For example, if someone is looking for a special local health service or care services like local care community, they could search by their postcode. It provided relevant information on communities around their situation.

Connect was a resource help point/guide providing ‘how to’ information for today’s digital tools to help people find ways of easily connecting to family and friends and their local health and wellbeing services, as well as connecting them with each other. It was a resource help point/guide providing ‘how to’ information for digital tools to help people find ways of easily connecting to family and friends and their local health and wellbeing services, as well as connecting them with each other.

Flourish was an interactive tool to support the patient by giving information and products that users could use to feel healthy and live independently at home. It was a suite of interactive tools to support self-management of long-term conditions. The interactive tool provided plans and encouraged patients to take up healthy habits, such as walking. It included ‘experience guides’ from trusted NHS resources.

“The fourth service is a service called Flourish and that’s very much relating to health and care and wellbeing. So, what keeps you well and if you start with a population that are well then what keeps them well is being more active, getting more involved in their community, so if they don’t have a long-term condition we still want to keep them active and well because then it can delay the onset of a long-term condition. So, for that, we have a range of tools, we have things like are you having a good day, so that’s very much based on your mood, so is this a good day for you? What did you do today, and it’s just a kind of logging, tracking system for, I would say for kind of your mood. The second things we have is the Keeping Active and Community Challenge. So, keeping Active is for them to allow to track what activity they’re doing, whether it’s walking, gardening, looking after their grandchildren, hanging out their washing. We’re not talking about marathons or running. This is low level activity, rather than sitting on the sofa and watching telly, what have they been doing, and it tracks that, it keeps a log of that activity.”
(Programme manager)

During the co-design of this service, the name of this service was changed from MyCare to Flourish. One particular tool in Flourish was GetActive, which was a service with the aim of promoting and supporting healthy activities for targeted individuals. Another service of Flourish was called “GetActive”, which was also a remote home monitoring service that used text-messaging alerts to guide users who were staying at home alone. Four target topics were borne in mind in relation to this: 1) Independence: targeting users to stay independent at home and in their community; 2) Health and lifestyle: improve health and wellbeing knowledge and using tools to help them manage their health condition; 3) Share user knowledge: gaining knowledge from others and sharing client’s experiences on a variety of subjects; and 4) Keep active: getting up and about, tracking clients activity levels and taking up the activity challenge.

Flourish shared the information between users as well as carers:


“The other aspect which again I think is a kind of social media concept is the experience guides which sit in Flourish and they’re generated by the community. So, you can have an experience guide on dementia or lung conditions and what that allows is people to share their experiences with others, what worked for them, where they got really good resources, what they found was useful, what they found wasn’t useful so it’s quite an easy to understand kind of tool that can be printed out for people that have maybe only been diagnosed with dementia or a carer with dementia. This is also for the carer’s community I know that you mention that so to support them in looking after people with a long-term condition.” (Programme manager)

6.4.2 Selection of online web services (new social media)

In this section, I examine four online applications (elaborated on in Table 6-5) developed for health and care in the UK.

#	App Name	Duty	Users			Web Service	Mobile App	Coordination Goal	Organisation	Application Elements
			Professional Carers	Carers	Patients					
1	Our Big Box (terminated)	Alzheimer patient	X	X		Yes	No	Memory reminder with family photo	The Memory Box Network (charity)	<ul style="list-style-type: none"> - Upload pictures with captions - Make patients' circuits - Family access for uploading family's pictures - Shows albums and pictures - Post/ask regarding the individual's condition - Coordination between family and carers - Free service
2	Healthunlocked	Health social network		X	X	Base	No	Online communities –	Profit company	<ul style="list-style-type: none"> - Online communities - Find related communities - Personal page - Following other people - Coordination between patients and carers to solve/share their experience - Post related to their condition - Free Service
3	Babylon Health	Online health service		X	X	Limited	Yes	Connect patient to DR	Profit company	<ul style="list-style-type: none"> - Conversation with patient to connect them with a GP or... - Set an appointment with GP/Specialist - Monitoring your condition - Family control - Paid app
4	Jointly	Care application		X		Limited	Yes	Care coordination app	Carers UK – charity	<ul style="list-style-type: none"> - Circle care - Schedule for a patient - Task, message and note to each carer - Medication information of patient - Contact page of patients - Paid app

Table 6-5- Specifics of new health and care applications



Register | Log-in

OUR BIG BOX
Sharing Stories

Log-in to OUR BIG BOX

Register for your FREE Our Big Box account

Watch six year old Anya's story

OUR BIG BOX sharing stories and connecting loved ones living with dementia

What is OUR BIG BOX?
OUR BIG BOX is a completely free online reminiscence system provided by The Memory Box Network, a dementia related charity based in Scotland.

How does OUR BIG BOX work?
OUR BIG BOX uses pictures to help connect family and friends through conversation and reminiscence. Personal pictures can be uploaded to the system and combined with others drawn from our growing library of images provided by our digital archive partners.

How can I get involved?
Start using OUR BIG BOX today:

Register today for your FREE unrestricted account.

Donate to OUR BIG BOX

PARTNERS
Funders and friends
Become an archive partner
Archive partners

TERMS & CONDITIONS
Terms of use
Privacy policy
Acceptable use policy

ABOUT US
We are a not-for-profit charity
The Memory Box Network

CONTACT
Contact Our Big Box
Media enquiries
Sign up for our newsletter

Figure 6-8- OurBigBox's screenshot

6.4.2.1 Our Big Box

Our big box was an online reminiscence system provided by The Memory Box Network, a charity based in Scotland. The aim of the application was to help families and friends of people living with dementia to help the patient with Alzheimer by stimulating conversation and inclusion through reminiscence. It was a web-based application, using pictures, conversation and reminiscence for the target patients. The pictures were shown by the carer (informal or formal) to the patients. The aim of the application was not to cure dementia patients, but there were creative and engaging ways to help them improve the quality of their life. It was a 'digital treasure chest' to which memorable photos could be saved. Personal pictures could be uploaded to the system and combined with others drawn from system's growing library of images. The pictures could be shown by different devices like tablets or smartphones. It was aimed at improving psychological health by stimulating reminiscence and interaction.

By using personal pictures and pictures from partner libraries and this memory application, those living with dementia could connect with family and friends through conversation and reminiscence to avoid individual isolation from everyday life.

This website made coordination between formal and informal carers possible to help patients to cope with their condition. This service was terminated due to financial problems.



Figure 6-9- Inside of OurBigBox

6.4.2.2 Health Unlocked

Healthunlocked is a SNS that holds over 600 different health and care online communities for wide range of health and care and wellbeing conditions and has over 2.6 million members. Patients or carers with any condition can register on this, create a profile and join any online communities where there is a match with their condition. Many of these online communities are run in partnership with other health organisation or charities e.g. BLF, British Liver Trust, and Endometriosis UK. So, this application facilitates the connection and coordination of organisations with each other or with a patient.

People with similar health backgrounds can address day-to-day health concerns together. It uses the concept of SM (forums or groups like FBGs) to create a peer-to-peer support network for patients, caregivers and health advocates and to connect them online with guidance from credible organisations and institutions. They use this application to talk about their experiences of conditions, symptoms, treatments, and health services. These are catalogued in an intelligent database which signposts relevant content to people based on their profile.

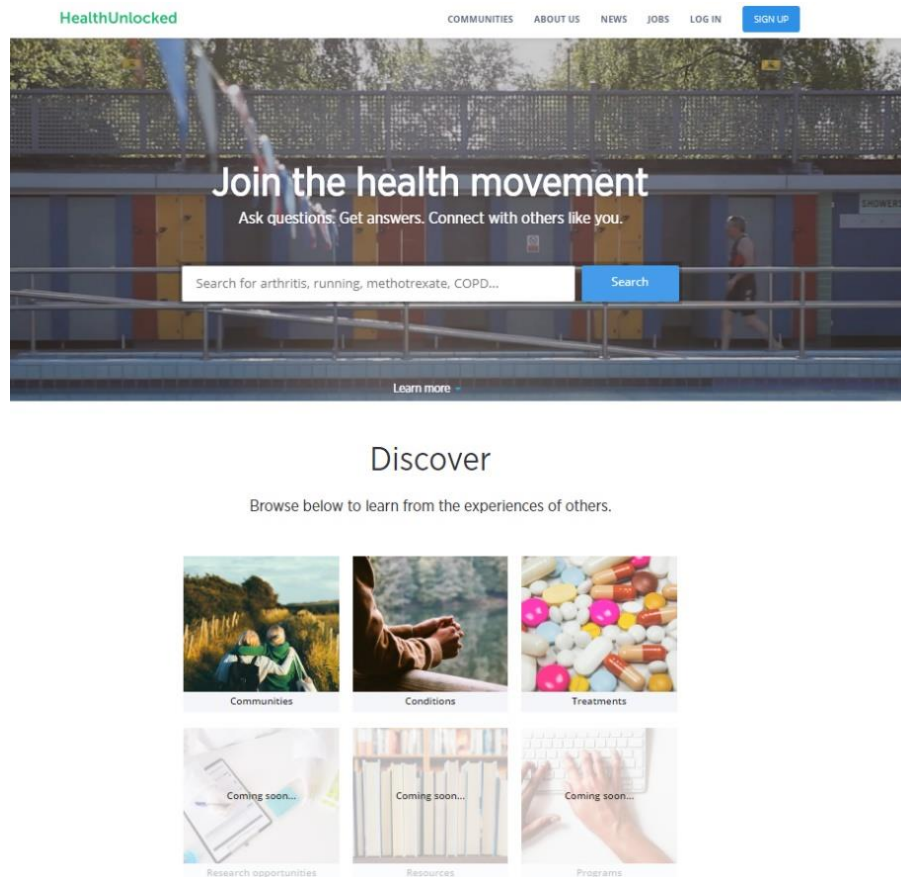


Figure 6-10- Healthunlocked's screenshot

Over the first six months of 2017, 50M people, mainly from the UK and US, visited this website. This application has about 650,000 members and around 4.5 million users visiting it each month (Healthunlocked, 2017). It has around 700 online health and wellbeing communities across around 200 conditions. These provide dedicated help, support and information for patients. Use of the site is free of charge for charities, non-profits, members and visitors. Healthunlocked recently started to use Artificial

Intelligence (AI) technology to provide relevant and targeted solutions and services to industry, pharmaceuticals and health and care organisations.

Healthunlocked is owned by a private company, which receives its main income from 1) research and 2) development of applications used by clinicians. Recently, the company raised money from investors to develop AI to support patients to better manage their own health by matching relevant and tailored health content, information and service to patients. The online communities enable patients to provide peer support for different conditions. With these online communities, patients and carers improve their knowledge, helping individuals to cope with illness and disease. This application is currently functioning in the UK.

The screenshot shows the Babylon Health website. At the top, a blue navigation bar contains the text "Learn how you can see an NHS GP in minutes, for free." with a "Learn more" button. Below this is the Babylon logo and a menu with "Features", "About", "Blog", "NHS", "Sign in", and a "Download app" button. The main content area features a large image of two women in an office setting. Overlaid on the image is the text "About babylon, our vision and our people". Below the image, the word "MISSION" is written in small letters, followed by the heading "On a mission to transform healthcare for everyone on earth". The text below the heading reads: "babylon was founded with a single purpose: To put an accessible and affordable health service in the hands of every person on earth." and "How? We'll do this by combining the ever growing computing power of machines, with hand-picked medical experts to create a comprehensive, immediate and personalised health service and making it universally available." A "Learn more" button is located at the bottom of this section.

Figure 6-11- Babylonhealth screenshot

6.4.2.3 BabylonHealth

Babylon Health is a subscription health service provider that enables users to have virtual consultations with doctors and health care professionals via text and video messaging through its mobile application. The service also allows users to receive drug prescriptions, referrals to health specialists, and book health exams with nearby facilities. The users of this application are patients and informal carers. Patients can check their symptoms for a diagnosis, chat with their GP face-to-face via a video link and order prescriptions. This application is owned by a private company, with the main income coming from subscriber fees. The features of the application are:

- Consultations – Common medical questions can be addressed through this tool. In some cases, prescriptions can be provided for patients. Patients can also receive consultation from therapists regarding their depression or anxiety, and the professionals can be reviewed by the users.
- Health monitor – This synergises the app with the tracker’s activity for health monitoring. The data can be used for building a health plan for the user.
- Test and kits – These can be used for testing things such as diabetes, cholesterol and sugar levels for monitoring purposes.
- AI – AI is used to pre-screen the users' health conditions. It is powered by a chat-bot interface as a means of understanding the patient’s symptoms and directing them to the proper service. Also known as “GP at Hand”, it was launched as an alternative to the NHS 111 telephone service in part of London in 2017 (Heather, 2017).

The application facilitates cooperation between patients and GPs in order to save time, rank services and professional people, provide access to medical records and update medical bank records.

6.4.2.4 Jointly

Jointly is a mobile app for designing a circle for patients or informal carers who need to split or schedule care activities. There are specific aspects to this application, such as the feature whereby carers can contact each other or as a group. The care receiver has a page that includes all information that carers need to arrange appointments and

visits, such as the name of the individual's GP, their number, their medication list, a calendar and to-do list for sharing with all carers.

This application has a subscription with a monthly payment. It is developed by Carers UK, a charity-based organisation. This application effectively coordinates care between family and friends to give care service to patients in need of such services. This application requires the Internet coverage to work.

The image shows a promotional banner for the 'Jointly' app. At the top left, the logo 'jointly' is written in a red, cursive font, followed by the tagline 'Care together from anywhere'. To the right, there are two buttons: 'Log in' and 'Sign up', both in white text on a red background. The main part of the banner features a hand holding a white smartphone. The phone's screen displays the app's interface for a user named 'Barbara Valentini'. The interface includes a menu with options: Home, Barbara's profile, Messages, Tasks, Calendar, Medications, Contacts, and Circle settings. Below this, there is a section titled 'Your jointly circles' with a 'Leave' button and two entries: 'Barbara Valentini' and 'Monica Smaniotto'. To the right of the phone, the text asks 'Are you looking after someone?' and describes the app as a tool for making caring easier and more organized. A red button at the bottom of this section says 'Sign up to start using Jointly.'. Below the banner, there is a red bar with three sections: 'Brought to you by carersUK', 'Access Jointly from anywhere' with icons of a smartphone, laptop, and tablet, and 'Download on iPhone, iPad and Android' with 'ANDROID APP ON Google play' and 'Download on the App Store' logos.

Figure 6-12- Jointly screenshot

6.5 Co-production through new social media: needs and challenges

My research highlights four groups of actors that need to be involved and who are closely affected when SM is used as a tool for health and care purposes: 1) policymakers; 2) health and care professionals; 3) communities and charities; and 4) patients and informal carers (Figure 6-13). Policymakers promote the need for integration of health and care and the use of telecare and telehealth. This leads to investments in this area by providing funding to develop new SM to support these

aims. My findings in this section point to the roles and challenges involved in engaging two of the main actors: patients and carers, and health and care professionals.

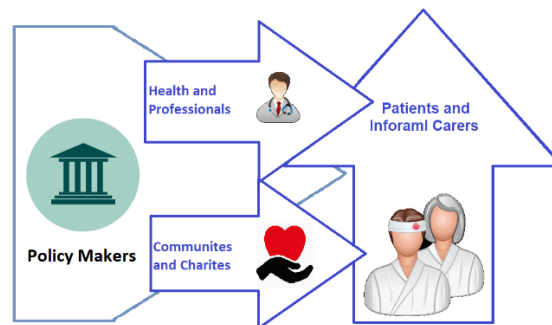


Figure 6-13 - Health and care actors
(Author's own 2017)

6.5.1 The health system needs to undergo change

My findings highlight the importance of the need for change in relation to the attitudes of patients and carers - as well as that of health and care professionals - to adopt SM in a way that supports co-production. The next two sub-sections explain this in more detail.

6.5.1.1 Co-producing needs to start from involving users in co-design

As mentioned in Chapter 2, the NHS is one of the largest employer organisations in the world (Stimage, 2018). In Scotland, the budget of the NHS was £12.9 billion in 2017, with 140,000 employees (NHS_in_Scotland, 2017). Due to this large scale, any changing of practice in the NHS will be costly. Policymakers have made large investments in the design of new health and care SM and new health and care services. Policymakers have used the concepts of co-production (in particular co-design) to design new systems or services in order to enable better co-delivery of services. Through co-production, the users become involved in all processes of service design to service delivery and evaluation:

“you’re designing a service that’s based on people’s needs, and it’s come directly from what people have identified as being a need, and it’s not something that, you know, a policymaker or civil servant has dreamt up”
(Programme manager)

The co-design process, conducted with the intention of getting the service fit for purpose, allow the opportunity for users to be involved in redesigning the processes and facilitating their ability to change the service to meet their needs. Through co-design, users are able to be involved in every step of the process. For example, a system which was initially named as ‘MyCare’ (by designers) was changed so much that it was even renamed by the users to ‘Flourish’.

However, enabling this act of co-production (co-design) is not without its challenges. In order to co-design, users need to have real involvement in the design and development, rather than just an explanation of their needs. This would require a lot of time and dedication by users and developers.

“asking someone what they think is not the same as truly involving somebody in the whole process from start to finish of co-designing or co-producing something together, and I think it's very difficult, it's a huge challenge that people don't get when something is or isn't co-production, and I don't know how you tackle that” (Programme manager)

Therefore, co-production activities are costly and need to be factored in, but, in the long-term, the costs have the potential to be outweighed by the benefits. An issue here is many co-design activities come from funded projects (e.g. LiU) and so there are very expensive co-design processes involved that are not necessarily sustainable.

A challenge in enabling this change relates to the fact that some stakeholders do not have the same understanding of the meaning of co-production and why there is a need for it

“I think a lot of people don't understand why we're doing it. I think they just think it's health and social care together; it will be better, but they don't know why it will be better... So, I think people need to understand why we are doing it, and why we work in a co-productive way.” (Programme manager)

There is therefore a need to redefine co-production and the reason for system redesign and new modes of delivery. This definition requires to go beyond academic

characterisation, and instead be given a practical meaning where needs and challenges are clearly explained. And the rule of co-production in addressing these needs to be clarified.

“I think the challenges really with co-production is people understanding what it means: it’s a jargon word, it’s a buzzword, even down to the level of whether or not the government are going to fund our work in the future, a lot of that’s based on the fact that people even within government know it’s written into policy documents but they don’t get what it’s about; they just think it’s just this buzzword, it’s come from literature, academic literature; it doesn’t really mean anything in the real world, maybe they get focused on other things like engagement or participation and involvement...”
(Programme manager)

As an initial step, attempts have been made to simplify the meaning of co-production and explain it in practical terms. However, even explaining the concept of co-production has been challenging as it creates lots of confusion about different underlying concepts such as the meaning of resources and assets

“we’ve got lots of areas explaining some of the terms on our website, we try to keep the language very simple, we don’t use too many academic terms and things like that, but even then, words like asset mapping, people don’t understand that.” (Programme Manager)

Another venture is to ask patients to encourage their circle of care to be involved in the use of the systems and services.

“...you ask four or five of your circle of care to join it, it could be family, it could be friends, it could be your hairdresser, it could be your gardener, and it’s just a very simple tool and I’ll give you the links to all of them, and feel free to register on all of them and try them out, and it just really allows you to coordinate and say “I need to get to the specialist on Tuesday of next week; can anybody take me?” It’s got a simple diary facility and scheduler, and allows you to do that or just communicate with people...” (Programme manager)

This motivates people to become active in the process because it forms a care community from which they can also receive service. This raises another challenge, which is that users need to feel that their contributions are valued, and users need to feel that they are rewarded for the effort they put into this venture (Cahn, 2000).

6.5.1.2 Co-production needs change in the health and care system

The health and care system is associated with many challenges and conflicts. As I mentioned in the literature review (Chapter 2), the government (policymakers) in the UK decided to redesign this system through the concept of co-production by re-designing towards a person-centred system. One important challenge is that all stakeholders must accept the need for system redesign. This means that the output should be tangible for all actors.

“Traditionally, people have always done things to people, so we have developed the NHS, local authorities have developed services, and just come out and said “this is what we offer”, “this is what happens”, and it’s not person centred, which is very very... the current terminology, actually, is not about a service, it’s not about person fitting, the service, it’s the service should fit the person, and I think people find that really challenging, because I think they have a fear that if they have to start providing lots of different options it’s going to be really expensive, whereas in actual fact, it’s not, because if you provide what a person needs then you will hopefully prevent anything, worse things happening moving forward.” (Programme manager)

Another challenge in the redesign of services is that due to the particular nature of the health system (relating to safety concerns, regulations, bureaucracy and the huge scale of the organisation), the health system is slow in terms of the development and acceptance of change. Some of these reasons are due to the sensitivity of human health, safety and confidentiality. Other reasons have roots in cultural issues and resistance to change:

“For us it is that the NHS moves quite slowly for lots of reasons that are defensible. The large bureaucracy with massive burdens on it, in terms of

trying to keep people well. So, the NHS moves very slowly, some of the mentalities are very old fashioned, very conservative with a small (...) the culture is ingrained. That has been our largest challenge.” (Business developer)

This problem results in a significant obstacle for IT developers seeking to develop new health and care technologies for such a slow market. On the one hand, a large number of private companies that offer digital health solutions are used to providing services to other sectors that are not as complex as the NHS (due to factors such as safety, ethical approvals and rules and regulations). Developing digital solutions, having due regard to these challenging factors, is very slow (Lennon et al., 2017).

On the other hand, the issue becomes more challenging when stakeholders do not trust new technologies and do not have time to adopt to change.

“That’s the biggest challenge, and the biggest barrier is getting the [clinician side on board]... and it’s GPs out of all health professionals... the biggest resistance is coming from these GPs who are “I don’t want that,” “I don’t want to be responsible for that”, “I don’t care about that information”, “I don’t want to see that graph”, “I didn’t take that blood pressure measurement”, and we do come up against that, and they don’t like things to change, and often the busiest professionals don’t have the time to change stuff.” (Programme manager)

Furthermore, health professionals also indicated that, in their view, much of the online data are not trustworthy. They therefore discourage their patients from accessing such data in relation to their health issues.

“If you go to a health professional and say, “I spoke to somebody on Facebook and they told me blah blah blah”, they’ll be like “don’t believe what you read online”, “don’t go on the Internet”. That’s the immediate response...” (Development manager)

As a result, in many cases, the real obstacle to change comes from the professionals. Professionals look for evidence and web-based material is often presented without such supporting evidence.

In several cases, study participants reported that convincing and training patients to become involved is not a big challenge. Instead, for many years, informing and persuading health professionals has been an ongoing issue.

“[...] getting GPs on board, getting medical staff on board, getting awareness pushed through general practices [...] anything that’s a potentially moving part is a problem. Most of all is definitely just, is getting GPs on side to then notify their patients, I mean this is the thing. We still get patients I had one two days ago who contacted me having difficulty logging into the site. That’s no problem, we’ll get that arranged and set up. They did that. They then came back to me and said, “I asked my GP practice about this and they said that they’ve never heard of the site”. So, we contacted the health board and the GP practice and had to explain what we were, that the system that we use is actually us and they were “ooh, we never knew” and again this service has been going for about six or seven years now and we’re still stumbling over the same blocks so it’s all about awareness and that’s the problem.” (Software developer)

The issue becomes more complex as the governing body, the NHS, restricts the use of many of these applications and services within its premises (in hospital, surgeries, etc.).

“[The big barrier is] I think actually NHS because they don’t have access to social media.” (Programme manager)

“I’d really like to develop this some more because I think it’s very relevant to a lot of policy work that’s around at the moment, the government want people to be more in control of their own health. They want people to take charge of their self-management, they want people to have access to peer support, but there are not quite services, the statutory services are not quite on board with social media yet, a lot of third sector organisations are

embracing it, they've got Facebook groups they've got chat, sort of sessions, online nurses or something like that, but they'd want, you know, the health services (NHS) are not offering that yet." (Development manager)

Some interviewees believed that although general SM is restricted by the NHS, new SM is designed specifically for health and care applications, and this can be seen as a possible solution in which the NHS (and consequently health professionals) can focus on dealing with trust and data protection issues. However, despite the potential benefits, there are many barriers for entering this market. In particular, this is due to costly regulations in getting approval from health authorities to work in the health and care sector.

Furthermore, introducing these new systems leads to a re-distribution of power. Redesigning services with the concepts of co-production or person-centred concepts changes the power relationships of different actors (patients, carers, health professionals). This shift (and sharing) of power, which results from sharing of decision-making practices as well as access to information by patients and carers, is not welcomed by some actors. For instance, health professionals are concerned about putting patient safety at risk by sharing the power, whereas some decisions makers have other concerns, such as losing control of what is happening.

"There's also something about power. I think people feel that if they share the power, and let's all develop it together, by relinquishing the power, that they're losing. I think, quite a lot, particularly with bigger statutory bodies, they think that we've always... we've always had control, we've always been able to do what we want, and now we have to ask people, and we have to work together, and that's a new concept for a lot of people, that actually the more power you share through the system, the better it will be, so there is a fear but I think that if people understand why we're working together, and what is the problem that they're trying to solve together, then it will make it better." (Programme Manager)

Essentially, the system requires to acknowledge that the decision-making process occurs on a spectrum of medical evidence and social feeling: the more “medical” the decision-making process, the more doctors feel that they have the right to take an evidence-based decision; the more “social” the decision-making process, the more people want to be involved in making the decision.

Overall, some stakeholders express a negative view on this matter.

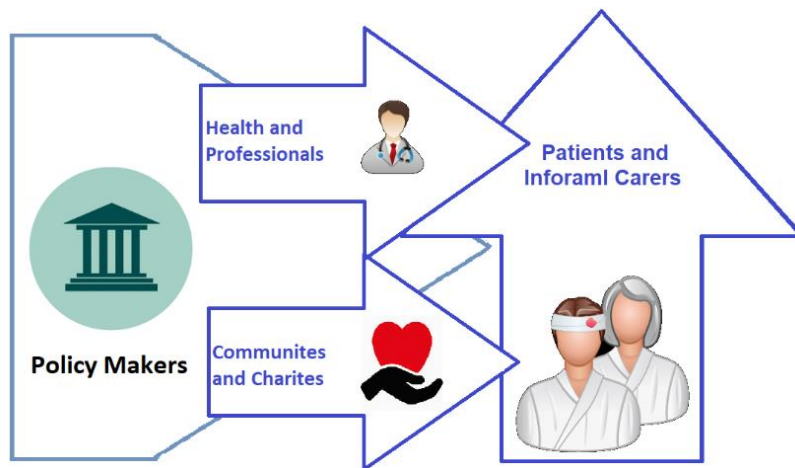


Figure 6-14- Health and care actors
(Author's own 2017)

6.5.2 Challenges in the use of New Social Media/applications for health and care purposes

In this section, I focus on the New SM developed for health and care purposes (the applications having been discussed in section 4.1) and explain some of the major challenges involved in the use of these applications. In general, a primary challenge was to get people started on the use of such applications, because in order to obtain values back from any system, it requires to be put into use.

“... you need to have people using it, and that initial challenge is true of any system... Getting started, it's overcoming that initial inertia and barrier...” (Manager)

However, studies show that, despite the widespread use of SM among many individuals, there are a large number of deliberate non-users (Baumer et al., 2014, Turan et al., 2013). Many reasons contribute to this lack of use. There are also many

causes for limited or cautious use of SM. In this section, I present some of the most prevalent reasons.

6.5.2.1 Applications trust

In Chapters 4 and 5, I showed that many patients and carers use general SM for health and care purposes. For instance, private FBGs are broadly used by patients and carers in order to share and exchange experiences, knowledge and skills with people with similar conditions. As those applications are not developed for health and care, users share their data at their own risk. Nevertheless, these applications have their own regulations about data security and safety. However, the issue of sharing of personal data on a public general SM (like Facebook) was a big concern for some users. Instead, they preferred sharing personal data on a platform dedicated to health and care:

“... we found people don't like, often don't want to do that kind of thing on Facebook, they have a resistance to it and a fear that their information, even if they joined a closed Facebook group, is going to get hacked or going to get, they don't feel comfortable sharing personal details like their movements and stuff, so that's why we developed... to support that.”
(Programme manager)

In essence, they do not trust general SM. The challenge of mistrust is even more evident in the elderly population (Fox and Connolly, 2018). New SM for health and care are therefore developed as a secure place where users can share their details and information with their family and their friends. Patients or carers can make a circle of their trusted people for their health and care purposes and share their information with this trusted circle rather than the community at large. There are several levels of data-sharing specific to health and care purposes. This new approach increases the trust in these applications. However, it also increases the cost of maintaining these applications.

6.5.2.2 Data accuracy and validation

Digital data is one of the controversial and sensitive topics in the IT sector, particularly in relation to health and social care. One major concern pertains to data accuracy on SM. Although digital applications can control and check validation with regard to data

format (e.g. dates, numbers, characters, etc.) they cannot examine data accuracy in terms of whether the entered data is correct or not.

“I mean you can do things like put good validation on pages, so you can ensure data is in the correct format, but you can’t ensure correct data entry. Now that means that you can differentiate between the data entered and you can decide what level of confidence you can draw from it.” (Business developer)

However, in the development of new SM applications, developers seek to address this issue by explaining the benefits of data collected by patients, or other uses of SM by patients and carers.

“There needs to be more work around helping health professionals to see it [online SM area], and not as a challenge, as something that’s going to really assist them, that’s going to be a collaborative relationship with people, don’t be afraid that your patients are going on social media, because it’s going to happen whether you like it or not, so you might as well embrace that.” (Development manager)

6.5.2.3 Data security

One of the biggest risks around data in this field is data security. Companies believed that:

“the biggest challenge and it’s a data risk, and security is the big one” (Programme manager)

Essentially, digital transformation is seen as the initial point for data protection challenges:

“so as soon as you have the idea of transferring patient data electronically you have inherent risk in that... Now the flipside is arguably any digital solution isn’t more secure than a paper book.” (Business developer)

Another major concern for data security and protection is data leakage.

“There is always a risk that that might leak out of the system.” (Manager)

This is particularly important because there is no control over the data that is shared by individuals. So, they can share their private data on public SM applications, such that this can then leak out to spaces in which it is less appropriate for this data to be accessible.

“The kind of harmful stuff that people could put in the public domain of social media.” (Programme Manager)

As a result of these data security issues, many health professionals avoid using these apps, or at least they use them in particular ways, for instance, by using SM as a general tool where they do not name patients (Thomas, 2018).

Governments in many countries, including the UK, have many strict rules about keeping health data secure to protect patients. These restrictions on data security and protection impose significant constraints on companies developing new applications. To meet all data security and protection requirements, these are different to different countries with different regulations. This in turn increases the costs and complexity of application development for international players.

6.5.2.4 Abuse of systems

Abusing the application or data kept within the SM is one of the risks in this area. Concepts such as ‘misinformation spreading’ are reported to have a wide reach through the misuse of SM. Several examples were highlighted by my interviewee participants. Examples include the sharing of fake pictures or use of fake identities to the sharing of inappropriate content or fake news.

“I think the main risk is around someone, because it’s freely available and anyone can send contents... Abusing the system, so using it either to upload inappropriate images and then sharing them across the system or using as a way of providing closed social network for purposes which are illegal and are aligned with our actual aims.” (Manager)

Or

“The former one was someone using it for a laugh, uploading photographic images and decides to share them is also quite a remote risk but it is one

that we take very seriously in terms of our reputation or of upsetting someone.” (Programme manager)

This risk seems to relate to the attitude of SM applications. This may be a reason for a gradual move towards more health-specific SM to help prevent fake news produced by open SM.

6.5.2.5 The Technical challenges

There were also many technical challenges highlighted by our interviewees. These ranged from challenges in the use of hardware, to accessing the appropriate networks. These types of barriers were experienced by different actors in various ways. For instance, having access to the right technology was a challenge faced by professionals in their health settings.

“Often the health and care people don’t have the right technology so they often are stuck in legacy systems that won’t even let them go into YouTube.” (Programme director)

Earlier literature also points to such phenomena as barriers to adoption (Thomas, 2018). Another adoption barrier was the user friendliness and usability (or lack thereof) in relation to the technology.

“For the users, we are obviously trying to design a service that is very straightforward and intuitive. An example of where it’s not been as simple as we’d like is the sign-up mechanism. So, for technical reasons of how the underlying software works, when you first sign up to e-Redbook, it can feel slightly clunky.” (Manager)

One final challenge relates to the unavailability of data in an offline manner. Most of the applications are web-based and require online access to the Internet for data to be accessible. I observed that in areas with limited or slow internet, many services, such as video streaming or uploading or downloading of pictures, etc., were unavailable.

6.5.2.6 Tensions between actors

In addition to the above-mentioned challenges in the use of SM, there were also tensions between different actors that hindered the use of such applications. The

primary type of tension between actors resulted from complexities relating to the management of common pool resources. As discussed previously, the extent of resources is finite, and there are tensions over how such limited resources can be distributed. While the use of SM could provide better access to some resources, non-use of SM could also prevent some individuals from using resources.

Moreover, there are conflicts occurring between users and many other types of actors, such as funders or policymakers. For instance, the requirement of funders for an application to gather user information was an obstructing factor in relation to the application's use.

“Because our funders want to know what age, what gender, what postcode, what bracket are you in? Are you a carer? Are you a GP? This then puts a barrier in the way of the user becoming engaged so we're in a wee bit of a Catch 22 where we need the information because you come to us and say “how many carers do we have?” But to get that information if you don't, if the user doesn't know, why would you want all that information? What's the value that I'm going to receive back? It's difficult to convince them so we do think that people are being put off by joining because of the length and the amount of information that we're trying to gather.” (Programme manager)

Another tension was resistance to use, both by professionals and patients (and their carers). For instance, elderly people were said to “prefer traditional methods” (Programme Manger). Even if it was for making a repeat prescription, “70% of people choose to speak to any GP... They can be repeat prescriptions, really simple things to do, you know, that free up GPs' time to spend more time with patients” (Programme Director). Resistance was also a concern for professional use as they presented various reasoning for non-use.

“A lot of the time we get resistance when we try to pilot it, because then we get things like: oh, our patients are too old.” (Programme director)

When the issue of non-use was not present, the use of the applications often resulted in tensions between various actors. One prevalent concern was the changing balance of knowledge between patients and professionals.

“When I visit my GP I get the impression that I know more than them at times. I’m living it, whereas they’re a general practitioner, not a specialist. It’s an odd place to be, and I’m know what I’m talking about, in part, due to social media.” (Patient)

On the one hand, this could be a valid concern of a patient, or just an impression due to an increase in knowledge that may or may not be perfect. On the other hand, the professionals did not always welcome the fact that the patients had this new knowledge.

6.6 Discussion

6.6.1 Summary of finding

This part of my research discusses how different types of new applications or SM developed for health and care enable co-production by supporting current services or developing new services. This chapter also offers insights into the challenges involved in the use of these types of applications as an enabler of co-production. Developers and organisations that provide health and care services to elderly people, carers and patients with long-term condition have developed various new applications and new SM to meet diverse needs. Initially, I discuss the large-scale DALLAS project. The project was a five-year programme that involved the development of applications and services for people with various needs. The project concluded at the culmination of my research. Through observations and interviews with programme managers of two subprojects (Year zero and LiU) out of four, I investigate the functionalities and use of these applications. Leaving aside e-Redbook, all of the applications have been either terminated or have radically changed in relation to either functionality or the intention behind the application. Evaluation of the projects demonstrates they were successful in the short-term, with LiU having particularly positive early evaluations (Generation, 2015). Some interesting findings from the early evaluation report for LiU, by Impact Generation (in April 2016), indicate that:

- 1) there was a reduction in the need for care services (specifically, a three-times reduction) in relation to active users of LiU;
- 2) there was a higher rate of volunteering in care, peer-groups and community care groups;
- 3) patients and carers felt empowered through use of LiU, feeling ‘activated’ in self-supporting their own long-term condition;
- 4) those involved in the LiU community felt that they could influence public policies and practices to deliver better health outcomes through digital means;
- 5) LiU met the majority of its service key performance indicators (KPIs) set within its management plans for 2015-2016.

Despite all these early benefits of LiU, and the meeting of the KPIs, after the funding of the project concluded, many of the programmes faced termination. Some parts were given to the third sector and some were taken over by NHS Scotland. The system did not hold together as a unified programme, with some services operating individually and detached from one another, and many others ceasing to function altogether. My observations show that no concrete plan was held for sustaining the systems in the long run. There was also another reason for the termination of the projects. LiU, which was launched for “redesigning and delivering new approaches” and “seeing how new ideas and technologies can improve the ways people live and transform their choices as they age”, required to fit into the surrounding situation. This meant that the surrounding environment also required to be changed. However, LiU did not consider this need in detail and it had a hard boundary with the “rest of the world”. Overall, the complications of health and care delivery, and the lack of plans for changes in the needs, regulations, and resistance of the health system, were among the problems that led to the termination of many of the programmes within the DALLAS project. This confirms the findings of Devlin et al. (2016), who published five key challenges for the DALLAS programme: 1) establishing and maintaining huge partnerships to deliver new health and care models was complicated; 2) there was a need for resilience in face of the changing external environment; 3) there were tensions between co-design and achieving delivery; 4) there were marketing issues for health and care consumers; and

5) there were many interoperability and information governance issues in relation to the applications.

I also examined four other applications (Table 6-6) that were developed privately for health and care purposes. Three applications continued to work and one stopped working before the end of my research. One of the functional SM developments was Healthunlocked, which used the format of the forum to share the experiences of users. This application was used by a wide range of users with long-term conditions, informal carers, communities and charity organisations (as concluded from observation). It coordinates some activities between a wide range of organisations, and carers and patients. It connects people with specific experiences and needs to each other to share knowledge about day-to-day health concerns and to provide peer-to-peer support. Some of these groups, forums or topics are administrated by some charity organisations or communities that worked on the specific topics.

Another functional application was Babylon health, which forged connections between patients and professionals (GPs, professional carers or specialists). This application allows for coordination between patients and GPs to save time, rank services and gives professional people access to medical records and the ability to monitor medical bank records. It has a subscription fee for its users.

Jointly was another functional application, supporting the building of a care circle for a patient in order to help informal carers to schedule tasks. It stored some initial patient’s information for sharing with carers.

Name	Duty	Status	P. Carers	Carers	Patients	Goal	Coordination	Organiser
Our Big Box	Alzheimer patients	Terminated	X	X	X	Memory reminder with family photo	Formal and informal Carers	Charity

Health Babylon	Connect patients to professionals	Available			X	Connect patient to GP and Professional	Patients and health professionals	Private
Unlocked Health	Connect users with each other	Available	X	X	X	Knowledge Exchange	Patients and carers	Private
Jointly App	Carers to carers	Available	X	X		Scheduling	Carers	Carers UK (Charity)

Table 6-6- New applications and social media for health and care

The last case that was developed by a charity organisation was Ourbigbox. It was terminated due to financial problems. Ourbigbox helped dementia patients to reminiscence by means of relatives’ pictures. This app helped carers to provide information through an SM tool to help people with Alzheimer’s to cope with their condition. It offered coordination between informal and formal carers to improve the care service.

These applications supported co-delivery. The applications were successful in delivering the service through different actors without all of the individuals knowing the meaning of co-production. Moreover, the new applications cover the reciprocity aspect, meaning that the users are inspired to help each other through this kind of application. They also define the skills and experience as a new valuable asset. Thus, users can feel the exchange of value through these systems.

I now discuss the changes needed in the health and care system in order to develop and use these types of applications. Policymakers have realised that the health and care system requires to be redesigned. However, the extent and complexity of the health settings, including safety-related issues, the evidence-based culture of decision-making in relation to professionals, the tension between specialist knowledge-based decision-making and the need to have patient involvement in decision-making all lead to further challenges in enabling the change to take place. Many stakeholders have not accepted the prospect of changing their practices in relation to the introduction of new

technologies and new services. The bureaucracy of the health system makes it very complicated for health professionals to accept the new technology. The fast changes in the IT systems also make this acceptance more complicated. Furthermore, some stakeholders (e.g. GPs and professionals) do not trust the new technologies. They believe that the new system does not have enough efficacy or safety. This is evident in general SM. Therefore, as more specialised health and care SMs are introduced, some of these trust issues become less prevalent. However, there is still a long way to go in terms of attracting the trust of health and care professionals in relation to these applications.

The redesign of the health and care system changes the distribution of power between different actors. Patients and carers can become more knowledgeable and more equipped to take part in decision-making processes. They become more capable in managing their own health and care. Some actors do not welcome this redistribution of power. Some are concerned about new safety issues, while others are resistant to changes in work practices.

Finally, I present some of the major challenges involved in the introduction of use of SM applications for health and care purposes. This set of challenges relates to trust, data accuracy and validation, data security and protection, risk of abuse, technical needs and barriers, and new tensions arising between different actors. The new SM application can help in reducing some of these risks. For instance, as the systems are dedicated to health and care, some of the trust issues and security concerns are lessened. The applications are designed around health and care data regulations, which lower some of the data accessibility and data misuse concerns. Yet, adhering to this particular health and care related regulations increases production and maintenance costs for the applications.

6.6.2 Compare findings to the literature

A large body of literature indicates that SM used for health and care purposes helps communication in relation to health (Moorhead et al., 2013, Egan and Moreno, 2011b, Lord et al., 2011, Rolls et al., 2016). Limitation in communication in health and care of SM relate to the quality of discussions (Adams, 2010b, Adams, 2010a, Friedman et

al., 2011, Hughes et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010), lack of reliability of the health information (Adams, 2010b, Adams, 2010a, Farmer et al., 2009, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010) and problems with confidentiality and privacy. My findings confirm these issues, but they also show that, when SM is designed specifically for health and care purposes, SM can also streamline some of these challenges. By no means am I claiming that all of these challenges are resolved. But I argue that health and care specific SM can increase the control of content, allow for some boundaries in relation to exchanges, and improve the privacy and confidentiality of patient information.

I confirm that the obtained and shared information has variable quality and consistency (Adams, 2010b, Adams, 2010a, Farmer et al., 2009, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010). Many scholars report that as SM refers to applications that are dynamic and two-way, and relatively unregulated, various ways of information collection, sharing and promotion with differing consistency are used that affect the quality of data (Adams, 2010b, Adams, 2010a, Clauson et al., 2008, Friedman et al., 2011, Hughes et al., 2009, Jennings et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010, Tian, 2010, Moorhead et al., 2013). In new SM, where patients or carers are located in a place with someone with similar condition, users report improved quality of information. Moreover, use of controls (by organisations and patients) can improve the quality of data shared. However, health professionals are still apprehensive in terms of the use of this information by patients. I argue that one way to overcome this is to involve the professionals in the co-design of the systems. This would mean that co-design is shared between developers, patients, and professionals. This has a dual effect on the outcomes. First of all, professionals (as well as patients) are informed about the benefits of such systems. Secondly, their needs and concerns can be addressed within the context of these systems.

Despite many studies on SM, adoption privacy concerns are not well discussed (Nef et al., 2013). In this study, I show that the issue of privacy in new SM adoption is a growing concern leading to new challenges.

Scholars report that SM-based health information broadcasting efforts have low costs (Chou et al., 2013) but, considering the numerous regulations and rules for privacy and safety of users, the development of new SM seems not to be effective in relation to the reduction of cost of those applications. Further research on this matter is required.

Finally, rather than just offering population-driven services (stratified medicine), many scholars call for patient-centric care and personalised coordination of services (Kitson et al., 2013, Stewart, 2001, Bauman et al., 2003). In this study, I show how new SM provides a platform for managing one's own condition and enabling coordination at a personal level. In this way, patients become involved in co-delivery of services, which is one of the important aspects of co-production.

6.6.3 Health and care service co-production through SM

Batalden et al. (2015) offers a conceptual model of healthcare service co-production (Figure 6-15). This model suggests that the interaction between patients and professionals is both supported and constrained by the health and care system and large-scale social forces in the wider community. Patients are part of the health system, but they are also beyond it as they interact outside its boundaries, which may effect the outcomes. First of all, I show that, in this model, SM has two important roles. It can enable communication and act as a tool that coordinates the activities of different actors. The relationships and coordination of acts within and between groups of patients (and carers), and professionals (health professionals and formal carers) is an essential part of making co-production happen. SM designed for health and care is an enabler of this. It can enable shared planning, a deeper understanding and appreciation of one another's expertise and assets, the improvement of trust, the creation of responsibility and accountability, and the sharing of workload between different groups. Secondly, I argue that, despite the many benefits of coproduced healthcare services, one cannot claim that good health is provided to 'all'. My research points to some new forms of conflicts and competitions that arise as a result of co-production. Therefore, whilst many improved outcomes may be realised, one needs to be aware of these new challenges to offer better health and care services to a large part of the society.

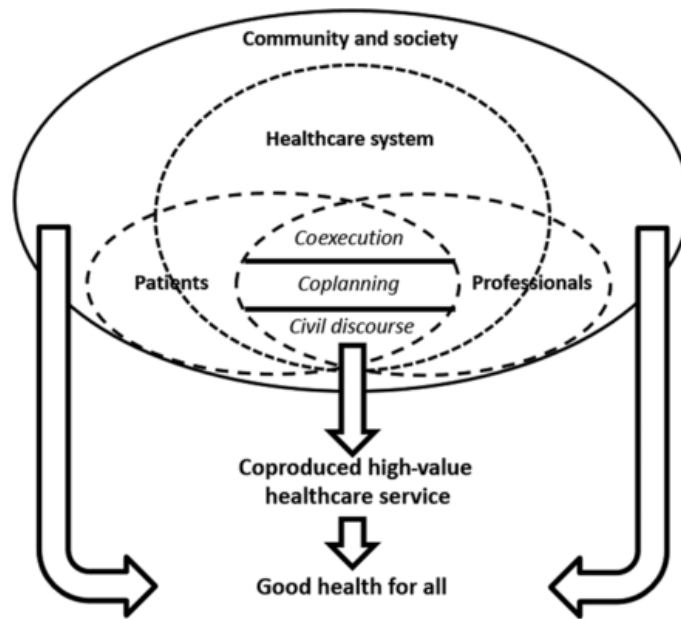


Figure 6-15- Conceptual model of healthcare service co-production
(Source: Batalden et al. (2015))

I argue that there are several challenges in facilitating SM to enable co-production. Both patients and professionals need to change their behaviour, practices and beliefs in tandem to move toward an effective reform of the services through the use of new technologies:

- Patient's knowledge and capabilities: patients have different understandings of co-production and the role of SM in co-production. They also have different capabilities and different health conditions, which makes them diverse in terms of being able to participate in co-production. Bearing in mind these differences, governments and developers require to educate patients and carers about the concepts of co-production and engage them in different activities and at different levels.
- There is a great deal of information available on SM. However not all of this information is helpful. The introduction of ways to (self-) monitor data, as well as informing users (patients and carers) that they need to be cautious in use of this data, is necessary. Moreover, education regarding the use and misuse of the applications requires to be made available for patients and carers.
- The new distribution of power introduced by SM is controversial. Many health professionals are concerned about the outcomes of shared power between the

professionals and patients. Health service reform is needed to help effective co-production relationships. This requires education, and changes to health and care regulations and work practices.

- One major concern of health professionals is the usefulness of the data produced by SM applications. Early involvement of health professionals in the design and use of these applications can help to make the systems more productive and reduce the resistance of the professionals.
- I also argue that providers of SM need to take account of the complexities of the health system and offer solutions that address complexities such as safety-related issues, rules and regulations, and conflicts of interest.

6.7 Conclusion

In this chapter, I discussed a range of new applications or SM that are designed to provide health and care services. Some of these applications transform a paper-based or offline service to an online service (e.g. eRedbook) and some introduce a new service or change the structure and the nature of an existing service (e.g. HealthUnlocked). I presented their functionalities and opportunities as well as the challenges involved in the design and use of these applications. I argued that both health professionals and patients need to be informed and involved in the design and use of these applications to enable the co-production of health and care services (from co-design to co-delivery). I showed that health and care services can be co-created with those involved in the health and care activities (patients, carers, and professionals). This co-production requires partnership and coordination between these different actors, which can be enabled through the use of SM.

While there are many benefits, the development and sustainability of many of these applications have proved to be challenging. For instance, we observe that several DALLAS sub-programmes were terminated after an initial development phase. Most of the terminations have applied to applications that were taken over by NHS or NHS Scotland rather than those applications that were privately funded. The reasons for the failure include a lack of clear sustainable plans for long-term running of the system (e.g. sustainable partnerships), lack of consideration of changes and adaptation to the surrounding environment (e.g. practices and regulations), and resistance to change by

professionals. As a result, to maximise the chances of sustainable use, there is a need to understand the complexities of the health and care systems and setting up clear partnership for enhanced health and care models. There is also a need to appreciate the changing external environment and its needs, and there is need for better publicising and management of change and having clear plans for information governance and sustained engagement.

To be sustainable the SM has to adapt to changes in context (i.e. what services, record information, etc. are available) and this poses problems. The amount of change in the health and care context is significant and, to some extent, out of the control of the hands of developers. The management of these projects makes the co-design of services costly, but services need continuous re-design and this is very challenging to achieve. Some changes, such as the re-design of the interfaces, are seen as wasteful and unnecessary by funders, while users are in need of such updates. Moreover, conflict between different silos of resource results in new apps or SMs being ‘squeezed out’ of the NHS. If we compare all of these challenges with the development of apps in the private sector, we observe many contrasting features. In the private companies, the context is under the control of the company and the app is a key element in the business model. The organisation of a company differs significantly from the NHS, leading to different project management models that involve limited co-design. Re-designing the apps (including interfaces) is seen as necessary to keep them looking up-to-date and desirable. Also, while in the NHS there are limited resources available for the uptake of products, in the private sector, considerable resources are spent on promoting the implementation and use of the systems. These contrasting features have led to differences in outcomes of the NHS and private company projects. Therefore, the health and care sector need to consider these issues in order to achieve sustainability of the products.

Finally, this view of ‘from co-design to co-delivery’ through ‘communication and coordination’ between ‘patients, carers, and health and care professionals’ can lead to the re-design of services and improved health and care outcomes where patients (and their carers) become more powerful and active in terms of managing their own conditions. However, it requires new organisational forms and structures for health

and care service design and delivery and new commitments and effort by different actors.

Chapter 7 - Application Framework – Carer Board System

7.1 Introduction

In the previous chapters, I investigated a number of different Web 2.0 and SM applications functioning around or designed specifically for health and care services. I discussed how these applications can help the co-production of health and care and the challenges involved in their continuous growth and use. In a significant number of cases, coordination and communication are identified as the key enablers of co-production.

In this chapter, I take a different perspective: I explore all of the data collected from a patient/carer perspective by identifying a number of common scenarios relating to the needs of elderly people and their carers and then showing if/how existing and new SM may provide a way of supporting different players in order to find a solution for these scenarios.

The scenarios identified below are extracted from the data collected in previous chapters and the results obtained around current and future health and care services. In this chapter, I present how Trello, an existing application designed for general project management and job coordination, can be functionalised for health and care purposes. The aim is to show that there are currently many existing applications that can be directed to cater for the health and care needs of the elderly, and they can provide new health and care services. In order to do this, I present the extracted scenarios, and then examine them to identify the underlying challenges and potential solutions. I then present how Trello can be used as a tool for these solutions. Finally, I highlight the barriers and challenges in the use of these applications and also the new forms of conflicts that arise.

7.2 Description of need scenarios

In this section, I begin with the presentation of seven problematic cases or needs in health and care of the elderly population. Each scenario is intended to capture issues

identified in the literature review, observation and interviews underpinning chapters 1-6 of this thesis.

7.2.1 Scenario one - Human contact

Chapter 3 identifies face-to-face meetings and communication as an important need of elderly patients and their carers. Although there is a large body of literature that argues that SM reduces isolation (Farkas et al., 2010), my interviewees expressed a need for face-to-face visits.

“Wrong subject, problem is not loneliness, it’s aloneness. That is the problem, and although my family phone every day to see how well I am, that is not the same as having a human contact. That is the bit that most people are talking about, going to the Internet, it is wonderful... I went on courses, I just did not like it, I like to speak face-to-face, have a discussion. I went out for coffee when my husband was ill, I took him out every morning, and it was wonderful, the way the girls in the coffee shop, chatting to human kicked in life, and honestly it is the aloneness that is the problem.” (Carer)

Patients, informal and professional carers all believed that SM cannot replace all face-to-face connections.

In this case, many elderly people who do not need 24-hour care by formal or informal carers felt that due to their condition, they were isolated from society. As a result, they need simple face-to-face encounters, or telephone or video conversations. There are resources available for face-to-face meetings, but it is scattered and difficult to use, in order to make a regular encounters. Informal carers or voluntary carers (e.g. neighbours or charities) may be able to offer short periodic time and support for communicating at different times of the day or week. However, coordination between different players is not readily available in relation to the effective allocation of resources.

7.2.2 Scenario two - Patient information sharing

Daily care activities for elderly patients require a large amount of information about their condition, wellbeing, allergies, etc. Formal and informal carers and health

professionals make decisions for patients based on this information. So, either one person needs to hold the information and act as a reference point for everyone else, or different carers need to learn this information and share new data to be able to provide care activities and avoid mistakes or confusion. For instance, where a family (several carers) are caring for their elderly father, different carers (e.g. sons/daughters) may visit at different points in time. They need to update each other in relation to the daily events, incidents, allergic reactions, medications, and other conditions of their father. In this case, there were several scenarios of the father requiring to take new medicine without this having been communicated to all of the carers. There was also a case of an allergic food reaction that one of the carers did not know about. Due to the occurrence of such situations, some carers refused to give further care as they were stressed in relation to the possibility of making a bad decision due to a lack of knowledge.

The gap in such situations is the lack of information sharing. The Patient Health Record (PHR) provides some good information. However, it does not provide sufficient data for day-to-day care activities. There is a need for the sharing of a wide range of information between different actors, particularly carers. For instance, a large number of elderly people or patients with the long-term condition require to take regular medication on a daily basis. Keeping to the prescribed programme is very important in the prevention of other serious or critical conditions. A common challenge is that when care is shared amongst a number of carers, they need to have up-to-date information about medication and whether this has been taken on time. Additionally, due to the possible change of informal carers, the history of medication and possible unintended consequences (e.g. allergies) need to be acknowledged by different carers so that, when visiting health professionals, discussions about these issues may influence the decisions taken for further care. Communication and coordination between different players is required to ensure that sufficient information is circulated between these players.

7.2.3 Scenario three - Identifying needs and meeting them

One recurring scenario is a situation whereby an elderly person cannot do his or her own shopping. They either need someone to take them shopping or do the shopping

for them. In order to facilitate this, informal carers (e.g. family members, relatives, neighbours) or volunteers from charities can help in different ways. For instance, by taking the elderly person shopping, doing online shopping for them or shopping and delivering the goods in person. There are many other scenarios similar to this one where an elderly patient has a particular requirement which requires a carer to step in. Patients requirements require to be recognised and acknowledged, and resources require to be found and allocated to fulfil these requirements.

7.2.4 Scenario four - Making the environment sustainable

An old lady, who lives alone, needs to replace a fire alarm battery that has run out. The alarm has beeped constantly, preventing her from sleeping. As a result, she needed someone to bring the alarm down as she was unable to climb a ladder.

In many scenarios like this, there is a need to maintain the living environment for patients in a sustainable way. Elderly people may need for semi-technical jobs (e.g. changing faulty lamps, repairing small household items, or setting up a TV or laptop), cutting the grass, or other maintenance jobs to be done that they cannot do by themselves. These kinds of jobs, which can be done by many ordinary people, can be expensive in the event that professionals are contacted. They need someone like a family member, relative or neighbour to help them.

7.2.5 Scenario five - The need for sharing of skills and experiences

I observed a case in which a man had to provide care for his wife who had recently experienced a stroke. Due to this new situation, he had many questions about daily care activities. In many cases, the answers to questions were not difficult for a person who had gone through a similar situation in past. But in this case, the husband did not have access to the people with relevant experience and knowledge.

In general, a key issue in providing care for elderly people with informal carers is that they need to have the knowledge and skills to provide the care. New carers may not have experience or knowledge about many conditions and, as a result, they may not know how to deal with the issues faced by patients.

In contrast, carers who have cared for or are caring for longer periods generally acquire valuable skills and experience in managing the condition(s) affecting the individuals for whom they are caring. I have observed several cases where the acquired skills were said to be very helpful for those people that needed them, although the carers with knowledge may not realise that they have valuable experience. A key need in co-production is to identify those with skills and experience and enable the sharing of knowledge.

7.2.6 Scenario six - Access to relevant information

An old patient who recently found out that she was suffering from pancreatic cancer had a need to do some research on the possible options regarding treatment. A relative started to search the Internet but he found a significant quantity of information relating to treatments, drugs, etc., and he was unsure of their suitability.

So, in summary, finding relevant and correct information about the different conditions is very important for patients or carers. The internet is one the most important sources of information. But finding the relevant and valid information and experience on the Internet may sometimes be complicated (as shown in Chapter 4). In some cases, incorrect information or information that may not be directly related to one's condition may lead to a more complicated situation. In addition, it has been reported that finding and accessing related forums or groups for the patients or carer is especially difficult for elderly people.

7.2.7 Scenario seven - The need for respite support

A woman providing care for her husband in poor conditions, 24 hours for 7 (24/7) days a week explained how she was isolated from society, due to full-time care. She explained that she could not go to any events. Occasionally, she received help from her son, although this was insufficient. She was therefore in need of rest, both in terms of her body and mind.

Patients and informal carers (especially those who care for elderly or patients in poor condition who need 24/7 care) may have to remain at home for long periods of time. In extreme cases, they may become isolated from society and have limited access to leisure or social time (examples of this having been discussed in chapter 4). These

carers require emotional support or the opportunity to share their feelings and conditions with other carers.

24/7 carers may also need support from other informal or formal carers to take periods of leave/rest. Such needs require coordination between carers and those who may provide respite support. In this situation, 24/7 carers need to gain some respite or need to travel for other reasons, but their obligations do not allow them to do this. Hiring a professional carer can be very costly. For short breaks, some other carer or relative can handle it. But finding or facilitating coordination between those carers as a means of gaining respite is complicated.

7.3 The underlying challenges and potential resolution mechanisms

The scenarios explained above point to a number of challenges, which are explored in this section.

Coordination: The first challenge is the lack of coordination between different actors, which is evident in the different scenarios presented above and in previous chapters. Effective health and care requires coordination across different levels and amongst different stakeholders (World Health Organisation 2008; Montenegro et al. 2011). However, as can be seen in the examples above, poor coordination, or its absence, leads to many difficulties in providing care, access to care, and efficiency in the distribution and use of resources. Enhancement of coordination between patients and carers or professionals is a necessity for improving quality of care (Saillour-Glénisson et al., 2017). However, coordination requires a large amount of resources.

Communication: Lack of adequate communication between different actors is another challenge highlighted in several of the above scenarios. Poor health communication channels in existing systems are also highlighted in the literature (as shown in previous chapters). Lack of communication refers to poor communication channels, as well as lack of communicative ability due to shortage of time, and the complexity of interactions between different actors.

Trust: Trust can be seen as another challenge in reaching effective outcomes in the above-mentioned scenarios. Trust consists of several aspects, depending on the actors

involved. For instance, on the one hand, health professionals do not trust data gathered by patients by means of their own research using technology. On the other hand, patients and carers are unsure of the public information that they can trust and use (Powell et al., 2011).

Access to information: In many cases, patients and carers face challenges in identifying useful sources of information or accessing information that could give them power. Having access to appropriate information can help patients make better decisions and empower them to discuss their situations with their health professionals.

Information, knowledge and skill sharing: An underlying challenge in a number of the above scenarios is the limited ability to share knowledge and skill. Furthermore, giving care (or self-care) can lead to the accumulation of useful knowledge, which can benefit others. However, this valuable knowledge is sometimes hidden, which means that the patients or carers do not even know that it exists. Limited knowledge and skill sharing is a challenge as it hides the assets that different people can use.

Identifying and accessing current resources: Identifying and finding the different resource is very challenging, but an essential task. Different resources include human resources, financial resources, and special resources.

- **Human resources:** As discussed in chapter 2, the value of informal carers is approximately equal to the budget of the NHS. Finding and being able to use informal care resources is an important challenge that needs to be resolved.
- **Financial resources:** Financial resources are needed for the provision of efficient health and care. This is because facilities and trainings need to be given to health professionals and carers to enable them to provide care.

7.4 Mechanisms in response to the challenges

In response to the scenarios above and using the findings of the previous chapters, I introduce a number of mechanisms that respond to these needs. Some of the described mechanisms below are adapted versions of similar mechanisms used in different applications.

7.4.1 Circle of care

The circle of care refers to the co-productive working of carers and patients to produce care activities. In a circle of care, different carers of each patient are identified (e.g. formal carers, neighbours, children, etc.), access to patient information is given to these individuals, they are then connected, and finally work is coordinated in this circle by the members of the circle. This concept has the potential to resolve some of the challenges relating to trust, communication and coordination, and provides a space where knowledge and training needs are organised.

The concept of ‘circle of care’ was originally used by Price and Lau (2013), who stated that an individual patient’s health and care system should contain the patient, providers, other actors, and the information sources (paper and electronic) related to that patient. I adapt this concept to flesh out the specific needs in order that co-operative work of carers, patients and other actors can be carried out.

7.4.2 Templating

Templating is not a very well explained concept. However, it is widely used by different applications. For instance, as explained in chapter 4, templates were used by charity and voluntary organisations for motivating users to share their stories on blogs in an easier way. Templates are also used for websites or Content Management Systems (CSMs) to make content creation an easier task.

I use the method of templating in order to paint the patient’s different needs for carers in a way that carers can choose between and tailor to meet their particular patients’ needs and conditions. Templates can be built up over time and provide a structure that coordinates work between different actors.

7.4.3 Time-banking

Time-banking was originally pioneered by Edgar Cahn in 1980s (Cahn, 2000). Time bank or time banking has been used in different situations, especially within social care systems. In this model, the currency is time. The participants ‘deposit’ time by giving help or support to others, and then they can ‘withdraw’ correspondent support when they are in need of it. Time-banks are mechanisms to achieve co-production. By

means of this mechanism, we give value to the assets of users, which is the principle of co-production.

7.4.4 Resource recognition

We need detection mechanisms to enable patients and carers to gain knowledge about the resources in their neighbouring environment. This information could relate to people's skills and abilities (e.g. similar to the ALISS website), communities around a person's neighbourhood or in the city, regular or ad-hoc activities organised for people of similar conditions, etc. This repository can be filled in by people, for people. Patients and carers can make clear the different abilities and skills that they can provide (e.g. dog walking) to offer to others.

7.4.5 Matchmaking (for human contact needs)

The concept of matchmaking was originally used for dating and marriage purposes. Later on, it was used in many different fields, such as information systems, to explain the process of finding appropriate matches between service requesters and service providers through an agent (Sycara et al., 1999). I use this concept in order to solve some of the challenges and needs discussed in the above scenarios.

- **Volunteering services:** Voluntary and charity organisations need volunteers. Some activities can be done by elderly people. Systems can be used to find and connect elderly people to charity/voluntarily organisations who need them. This can be on a regular or ad-hoc basis. Matchmaking mechanisms can be used to identify not-for-profit events and their requirements and make a match to the skills and availability of the elderly person.
- **Socialising:** One of the scenarios above was about elderly people in need of human contacts. We can use matchmaking mechanisms for connecting people with the same interests for more interaction. In this method, people introduce themselves in accordance with the different parameter to find someone else with a similar character.
- **Society/public in need of assets of the elderly (e.g. English language, home, expertise, ...):** An important aspect of co-production is finding the

assets and giving value to one’s assets. In this matchmaking of society/public, we need to discover the assets of individuals and assign a value to these. On the one side, elderly people have different assets. And on the other side, the society may have a need for their assets. For instance, the language (which may be English or another language) of elderly people can be seen as an asset of these people. On the other hand, some students (who have the ability to help in shopping) need to improve their language skills. Connecting these people can help in co-production. Another example is matchmaking between elderly people who have extra rooms in their properties and students who need cheaper accommodation. This can lead to lower costs for students, a source of money for the elderly, and reduction of isolation.

7.4.6 Patient care record

Information about the patient’s conditions, activities, needs, allergies, etc. is needed for their care activities. The idea is an expansion of an electronic patient record (Tang and Hammond, 1997). I propose making a repository of this information that could be shared with the circle of carers (as described above) based on different care levels and responsibilities. This is similar to patient health records, but goes beyond these by allowing the recording of patient’s everyday conditions to be shared amongst their carers.

#	Scenario	Problem and Need	Underlying Challenge
1	The need for human contact	Isolation from society and the associated need for socialising	Coordination, communication, trust
2	Need for patient information-sharing	Sharing information relating to the patient between different carers	Coordination, information-sharing
3	Requirement-identification and finding resources	Shopping is difficult for elderly people, who therefore require assistance or a shopper	Coordination, identification and access to current resources
4	Making the environment sustainable	It is costly to hire people for semi-technical jobs, and there is a need for someone to do these for them	Coordination, trust, identifying and accessing current resources, trust

5	Need for sharing of skills and experience	New carers and patient do not have enough experience and need support from former or older carers	Identifying and accessing current resources, information, knowledge and skill-sharing
6	Access to relevant information (access to information)	Finding the relevant information on the internet is not easy	Access to information, trust
7	Need for respite support	Full-time carers are isolated from society; the need for mental support or finding short-term respite	Trust, identifying and accessing current resources, communication

Table 7-1- Summary of all scenarios

7.5 SM for health and care

In all of the scenarios explained in this chapter, I observe a number of challenges, such as coordination and communication, as being the underlying issues that require to be addressed. Improved coordination is the key to better co-production of health and care too. We need a tool to address these challenges, starting with enhancing the coordination of activities between different actors in order to manage resources in a better way. Coordination is needed between a) different carers (formal and informal); b) carers and patients; and c) carers and health professionals.

#	Mechanism	Explanation	Response to
1	Circle of care	Identifying different carers and their level of carer	Coordination, trust, identifying and accessing the current resource
2	Templating	Creating some structures for content-generation	Trust, access to information, knowledge and skill sharing
3	Timebanking	Time is currency that is deposited as people give support to others	Coordination, identifying and accessing current resources
4	Resource recognition	Finding the people, organisations and events with their skills or service pertaining to the patient	Access to information, trust, identifying and accessing the current resource
5	Match-making (service)	Matching charity and voluntary organisations with elderly volunteers	Coordination, trust
6	Match-making (socialising)	Matching elderly people with each other for communication	Coordination, communication

7	Match-making (assets of the elderly)	Identifying and matching people (e.g. students) with elderly people with assets	Coordination, communication, trust, identifying and accessing current resources
8	Patient and carer records	Record patient information (daily information) to share with carers	Trust, access to information, knowledge and skill sharing

Table 7-2- Mechanisms

In this section, I argue that we do not need to design tools from scratch to meet the needs and challenges explained here. I propose instead that the current applications (SM, or applications using the broad concept(s) of SM) can meet these needs to a great extent if they are configured or customised for health purposes. Using these applications in an appropriate way can enhance better management of resources. I give an example of an application called Trello, which can be can be incorporated into practice to help meet many of the needs highlighted in the scenarios, and then I propose how this application can be changed or integrated with other existing applications to cover other needs.

7.6 Trello

Trello is an application developed for organisations and for personal use. It is designed as a whiteboard that holds some cards as ‘jobs’ on the board. Members can post ‘jobs’ on the boards, and every member can respond by ‘taking the job’ or ‘allocating others’ to respond. Trello is a collaboration tool that splits a task between a group of people. It was developed for project managers, but it can be used in various other ways such as for personal use, school bulletin boards, lesson planning, and accounting. It shows time visual overviews of what is being worked on, the progress made, how and who has done it, and what remains to be done. This tool organises jobs into a board, cards and lists. Trello describes its product as “a collaboration tool that organises your projects into boards. In one glance, Trello tells you what's being worked on, who's working on what, and where something is in a process”.



Figure 7-1- The initial idea of Trello

It works like a whiteboard with sticky paper to be picked by/allocated to different actors, with the board as a whole giving a comprehensive view of the work. Cards, which are the broken-down activities on each board, can contain deadlines, attachments, checklists, images, discussion notes and coloured labels. They can be searched, shared and used as reminders.

7.6.1 Trello in relation to supporting elderly health and care co-production

Trello has the potential to coordinate individuals to take up different activities in order to coproduce health and care. At this stage, I explain the configurations and customisations needed to use Trello for health and care purposes covered in each of the above mentioned seven scenarios.

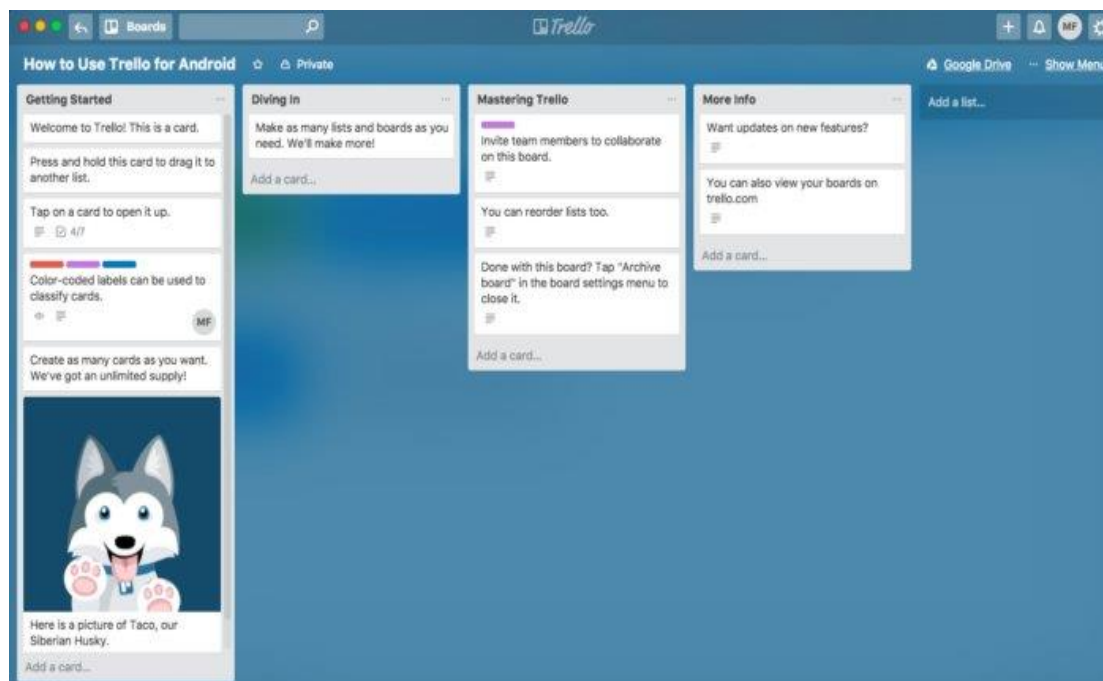


Figure 7-2- Screenshot of Trello

7.6.2 Trello as a response to the challenges

Trello can be used in many different ways for scheduling purposes (coordinating). It can be used to schedule recurring tasks or planning one-off activities. It can be used to allocate tasks to individuals, or to post tasks on a wall for individuals to pick up. In the next section, I will explain how to configure Trello to meet the needs of many of the above-mentioned scenarios. In some cases, I suggest expanding the current functionality to achieve improved outcomes. I have chosen this approach because repurposing an existing SM means that users are often already familiar with the SM and can easily adapt to its use. In addition, most SMs evolve as new functions are identified and changes to improve the user experience are implemented. Suggesting that we build on a tool like Trello in turn suggests that we can build in the means to evolve the application as app technology develops.

7.7 Solutions

In this section, I explore how a Trello-inspired tool could contribute in the collection of scenarios we consider. In the cases below, we identify two main types of scenario: 1) those considering the support of independent living for older patients who live on their own but require care/support for some activities; 2) those considering the support

of fulltime carers of an elderly person. In the following two sections, we consider two different means of repurposing of Trello with the aim of supporting each group.

7.7.1 Solution I - Independent living

As explained above, to reduce care costs and increase socialisation, we require to have a circle of trusted carers, such as family, friends, neighbours or voluntary workers to work in coordination with professional carers and health officials to support independent living of the elderly population. This circle of care will be the baseline for the design of my solution. Steps:

- A. Set up a private board for the patient on Trello: Mr John's Care Board.
- B. Add carers (members) to the list:
 - Jack (son)
 - Jill (daughter)
 - David (neighbour 1)
 - Kirsty (neighbour 2)
 - Sarah (voluntary carer)
 - Daniel (professional carer)

After setting up the circle of carers, the next stage is the scheduling and coordination between different actors. In order to do this activity, we need to be scheduled/recorded into the system. There are three types of activities:

a) **Monitoring**: recurring activities to be done by the patient, which only require to be checked by a carer (e.g. taking medicine);

b) **Recurring care**: recurring activities that require the support of a carer (e.g. shopping);

c) **Non-recurring care**: ad-hoc activities that require support from a carer (e.g. changing a lamp).

Here are some examples of how this will work (in response to the above-mentioned scenarios) and the unintended consequences of failure in each case. I then describe what happens.

1- Medication: Trello can be used to schedule medication times and send reminders to patients. Then, when medication is taken, this can be updated in the system. Therefore, if a dose is missed, all those who are involved in the care activity will know that the particular medication is not taken at the right time. In this way, they can send reminders to the patient to take the necessary action.

If a patient does not take their medicine and the system sends an alert to the carers, and if nobody responds to this, the system should issue or create a card or list for the next available carer to follow this up. If the medicine (or job) is critical (e.g. in the event where, if the medicine is not taken, the health of patient will be in danger), the system should send an alert to a professional carer. If professional carers do not respond, the system should then send an alarm to all (this is for very important occasions involving extremely important medicine e.g. medicine for heart disease). This provides a solution to coordination and communication challenges.

2- Health data: Trello can also be used to record patient care records, such as any unintended consequences (e.g. allergies, fatigue, pains) resulting from any medication or wellness/un-wellness. This can be shared amongst carers and also used as a source of information when care is discussed with care professionals. This helps to overcome information, knowledge and skill-sharing challenges.

3- Scheduling: Trello can be used to set-up recurring activities. For the above-mentioned scenarios, two recurring activities require to be scheduled:

a. **Visiting Schedules:** Visiting Cards will be set up at certain intervals (e.g. daily phoning and weekly face-to-face visiting). Anyone in the circle of care (including family, friends, neighbours, and professional carers) can pick up a card as they visit or talk to the patients. The system can be further expanded to send out alerts if visits/calls have not been conducted for an identified interval. In this way, Trello can be used to coordinate visits between different actors.

Similar to the medication solution, if no one responds to the card, the card can be allocated to someone by the system or by the key carer. If

the allocated person cannot do it, s/he can also arrange with someone else to take care of it.

- b. **Shopping schedules:** We can set up Trello to contain regular shopping activities. For instance, weekly grocery shopping can be defined as a card on the board (by a patient or a carer). Various informal carers, e.g. neighbours or family, can take the cards from the board at different times. This helps different carers to coordinate the shopping activities between them. Similar to the previous scenarios, if nobody responds, the key carer allocates the job to one of the carers. This deals with the coordination challenge.

- 4- **Ad-hoc activities:** Supporting activities, such as maintenance work, the changing of bulbs, one-off shopping, etc., can be set up as cards as and when required. These can be entered into the system by the patient or any of the carers with a time limit tag for carers to pick up. Anyone within the circle of carers who is nearby can pick up cards to respond to the need.

If the patient issues a card or request for an action (like shopping) and nobody responds, the system can allocate someone else at random. If the carer cannot provide the service, s/he can arrange with someone else to take it. In the context of this solution, coordination and trust are dealt with.

- 5- **Information markup:** Trello uses ‘#’ to sort and access data. This can be used to improve the accessibility and use of patient archives for patients, carers and health professionals. Access to information is dealt with here.

Carers and patients should keep the system up-to-date, but if they do not keep it up-to-date, then, similar to any other system, the data becomes unavailable for further use.

For this repurposing of Trello, we are aiming at substituting community (both real-world and virtual) resources for professional care resources. A critical potential inhibitor to the adoption of this approach as a substitute for mainstream approaches to care is the consideration of ‘safety’. We want to ensure that a whole range of ‘bad’ events never happens, suggesting that a number of generic enhancements should be made to Trello:

- **Demand-prediction:** for most critical tasks intended to be picked up by the community, there will be a care professional ensuring they are picked up within a timespan. For a care system to be safe, operations staff need to ensure there is sufficient professional staff to deal with anticipated peak loads (i.e. the expected maximum load on professionals arising from failure to pick up tasks in the community). This points to the need for a management interface that predicts demand into the near future to help plan effort.
- **Logging and analysis of past performance:** for different categories of task, we need to have an analysis of the proportion of effort provided by the community and what tasks are most often avoided by the community or undertaken easily. This provides the basis for effort planning and provides clues as to the training needs of the community to improve its capacity to co-create care.
- **Better capture of the need for tasks:** ideally there should be the means to capture the need using more modalities e.g. single button pushes to capture the need for common tasks.

One effect that would arise from this approach would be the surfacing of invisible work and unlocking the demand by easing the effort taken to express needs. This could have perverse side effects, such as the overloading of professionals with new tasks not undertaken by the community. Alongside the deployment of this type of coordination technology, there would need to be training of the community volunteers to cope with increases in demand.

7.7.2 Solution II - Full-time carer

In this case, the full-time carer becomes the centre of the care circle and, similar to above, coordination activities can be scheduled as recurring and non-recurring activities, or alerts with regard to medication. However, one particular scenario in this case is the need for respite care. With this app, a carer who gives care service to a patient on a constant basis can coordinate so that other carers to step-in if he/she needs to take a few hours/days of rest. The Trello circle of care can be used to inform others of the need for one-off care activities. The system can help to coordinate respite care between several carers if needed. The main carer can issue a card (several cards) to all

carers who are in this circle and other respite carers can respond to this card. This is convenient because the system also stores medication information such as allergies and times of administration, which can be used while respite carers step in. The circle of carers, time banking, and resource recognition mechanisms are used in this solution.

7.7.3 Extensions of Trello

I suggest that, in order to make Trello more suitable for health and care purposes, the system can be extended in various ways. The following four functionalities are examples of possible extensions:

- **Circle Levels:** The circle of carers is added to the board. Each board can be accessed by different circles and therefore information on each board will remain within the trusted bodies on the board. Trello can be expanded to create different circles for each patient with differing levels of access to information. For instance, there may be a ‘close circle’ for those who have access to all information, and an ‘extended circle’ for those who have access to certain data, such as shopping lists. This multi-level access can help by making sure that care is shared and coordinated between different people, but data remains with only those who have permission to see it.
- **Trello as a data analyser:** Reports can be designed in Trello to aggregate important information in a meaningful way such that it can be presented to health professionals, such as GPs and nurses. This results in better coordination of acts between health and care professionals. Patient care record is the mechanism used for this.
- **Alerts:** The system should monitor all outstanding cards and control whether they are done by a given time. If any carer cannot finish their job, the system should alert other carers to follow these up. For the cards that need to be done by more than one person, this must clearly explained in the jobs to minimise or eliminate any chance of conflict.
- **Templates:** A number of recurring activities can be defined as templates to be used by different patients and carers to facilitate easy data-entry into the system. For instance, a shopping template can be defined on a weekly basis, which can then be configured for each patient separately. This suggestion uses the templating

mechanism to respond to the trust, access to information and knowledge and skill-sharing.

#	Solutions	Explanation of solution	Mechanism	Challenges
Current Trello without any changes				
1	Independent living	Interduce and set up Trello for the independent living of a patient	Circle of care	Coordination
2	Medication	Scheduling systems for patient to take medication on time	Circle of care	Coordination, communication
3	Health data	Record patient care record about patient daily information	Patient care record	Information, knowledge and skill-sharing
4	Scheduling (visiting)	Scheduling for carers to visit the patient regularly	Time banking, matchmaking (socialising)	Coordination
5	Scheduling (shopping)	Scheduling for the patient to do the shopping with the carer	Timebanking	Coordination
6	Ad-hoc services	Support activity on the part of the patient	Matchmaking (service)	Coordination, trust
7	Information mark-up	Using hashtags for tagging and finding information	Patient care records	Access to information
8	Full-time carer	Providing respite care	Resource recognition	Coordination
Trello post-redesign				
9	Circle-level	Add a circle of carer to identify trusted carers around a patient with different levels of authority and information access; add a 'key carer' concept in response to mitigate some failure consequences	Circle of care	Coordination, identifying and accessing current resources
10	Data analysis	Report some information used by professionals	Patient care records	Communication, access to information
11	Alert	Monitoring all cards; if any card is not picked up by a certain time, the system sends an alert to the key carer and other carers	Circle of care	Coordination, trust
12	Templating	The design of the card as configurable templates relating to different activities	Templating	Information and knowledge and skill sharing

Table 7-3 - Solutions

In this section, I show how some methods in existing SM can be used in fulfilment of our goal. We can use the other mechanisms (e.g. time banking, matchmaking) to be used more in relation to the co-production concept.

7.8 Business model

This application needs to be implemented as an extension of Trello as a coordination tool. There are a number of important issues to be considered for the sustainable use of the application:

- **Membership model:** This application can be offered at two levels: firstly, a free membership option, and secondly, a payable option for extra functionality. The same model can be used in the case of health and care purposes. This prevents the issue of application termination we observed in many other health and care-related applications.
- **Adoption:** To encourage adoption, a range of health and care key services need to be available through the application. For example, if the ordering of prescriptions is enabled through the application, then individuals would be motivated to use it more frequently to receive other services and begin to adopt it for other tasks. Furthermore, organisers and trainers in the community need to start to organise community resources using the application and hand over to community organisers as users become better trained.

7.9 New challenges and conflicts caused by introduction of Trello

Introduction of a technology, such as Trello, into the care and health practices, in response to the needs and challenges described in the above-mentioned scenarios, presents a number of challenges. I categorise the challenges into a coding framework adopted from Creswell et al. (2018) around sociotechnical challenges involved in the adoption of technology in health and care, which includes a technological dimension, a social/human dimension, an organisational dimension, and a macro-environmental dimension (Cresswell and Sheikh, 2009, Cresswell et al., 2018).

7.9.1 Technological dimension

- **Infrastructure** – Problems with infrastructures, such as mobile/tablet/desktop and the Internet connection, may arise during use of the system by different actors. This can effect the usability of the applications.
- **Integration with PHR** – The lack of integration of data produced in this application with data from patient health records is an issue. This can lead to the duplication of data and a lack of data integrity.
- **Incorrect data** – Incorrect data entry can mislead different actors and can make the situation more complex situation for patients. It may result in complications for decision-makers. Mechanisms of templating is a way to reduce this risk, although it cannot be fully avoided.
- **System setup** – Setting up and running the system is another challenge faced in the use of the application. Elderly people or their carers may have difficulty in making an account or entering data into the system. Providing appropriate training and templating can help mitigate this challenge.

7.9.2 Social/human dimension

- **Trust** – Trusting the system is a significant issue for all users. As discussed in chapter 2, elderly people have varying levels of trust in IT. Lack of trust can lead to failure in the appropriate uptake of the system. Also, the lack of trust is experienced by professionals, as they do not have confidence in patient-generated data.
- **Integration into practice** - Technology needs to integrate into practice but in the health and care sector, due to the complexity of care and high safety issues, this is becoming increasingly difficult. The current practices of individuals (in particular, patients and carers) need to be changed to allow for the productive adoption of technology.

7.9.3 Organisational dimension

- **Ownership** – Application and data ownership is a longstanding issue in health care applications. In other words, the idea is to use an existing application for a different purpose, which poses the question of who would own the application and its data. Can the NHS or government form part of this?

- **The NHS and social care strategy** – Use of the application and its integration into formal health and care practices (e.g. use of data by professionals) is a challenging issue.

7.9.4 Macro-environmental dimension

- **Access to data** – Access to different personal information is a challenging issue in the health and care sector. In the case of the introduction of a technology such as Trello, different carers (e.g. relatives and neighbours) can access patients' confidential data. Circle of care mechanisms, and care levels are introduced as ways to manage data access by different individuals. However, control at different levels is still an important issue.
- **Data Regulations** – As mentioned in Chapter 6, in the case of applications developed for general purposes, the government and users have a certain degree of focus on data protection and security, but when it comes to health and care, data protection becomes even more important. Regulations need to be put in place in relation to data storage (e.g. EU or the UK), and data use by different people (e.g. health professionals).

7.10 Conclusion

In this chapter, I developed a range of scenarios of the needs of elderly people and their carers. In the majority of cases, there is a lack of coordination and appropriate communication between different actors involved in the care process.

I argue that existing SM can respond to many of the needs if it is configured and used appropriately. I give the example of Trello, an application that uses SM concepts for activity management and organisation purposes that can be configured and customised such that it can be used for health and care purposes. This application can be used to coordinate tasks between different carers (formal and informal).

In this chapter, we show that modest changes to existing SM can open up new ways of tackling a range of care tasks. Drawing on the example of Trello, I suggest that there are many existing SMs that can be repurposed to meet the needs of the elderly population. For instance, **KanBan** is another board system. It is a popular framework used to implement agile software development. It requires real-time communication

in relation to the capacity and full transparency of work. Work items are represented visually on a KanBan board, allowing team members to see the state of every piece of work at any time. These functionalities can be used in similar ways to Trello, to respond to the different needs in different scenarios. When comparing this with Trello, we found that KanBan has much more functionality, making it difficult to envision use of this application being an easy matter for the public. In summary, we looked into several applications and found Trello to be an example of a productive, efficient and easy to use SM for health and care purposes.

I conclude by stating that Trello, as an example of an SM designed for a different purpose, provides many opportunities for the health and care sector. It enables better communication and coordination across existing resources (formal and informal). I therefore suggest that re-purposing of existing SM innovations is a way forward for the better management of health and care services.

Chapter 8 - Conclusion

8.1 Overview

In this chapter, I integrate the findings of the previous chapters to articulate the overall contribution of the thesis. The chapter begins with an overview of the findings of each chapter in the thesis and how these findings cast light on the use of SM in health and care. This is followed by a discussion of the implications of the thesis for policy and practice. The chapter concludes with a discussion of the limitations of the work and suggestions for future research.

8.2 Outline of the thesis

As the number within the elderly population increases worldwide, there is a growing need for resources to meet the health and care needs of this population (Carretero et al., 2012). As a result, the governments need to invest to provide and deliver health and care services whilst the income of this population remains static or falls and they become more excluded from society. So, an important challenge relates to the question of how to reshape the delivery of health and care and make better use of resources for elderly people in the future. In order to do this, the concept of co-production is used by the Scottish government to better manage existing resources. Communications are a key element in co-production that enable coordination across various boundaries. SM helps to communicate across boundaries and it is widely used. However, the effects it has on health and care co-production for elderly care is poorly understood. This thesis investigated the current and possible future for SM as an enabler of co-production in health and care. In order to achieve this aim, I developed a two-dimensional model presented in Chapter 3 (Table 3-1), which points to the main areas of investigation in this thesis. Here, I highlight the main research questions of this thesis and summarise the findings of each empirical chapter.

Chapter 4 focussed on the question of how current SM supports co-delivery of current health and care services. I observed three types of actors involved in health and care services that use SM: 1) professional carers, 2) charity and voluntary organisations, and 3) carers (informal carers).

The findings show that professional carer organisations use SM for advertising or sharing information. These organisations would not engage in any activity with their professional carers through SM. However, professional carers are keen to improve uses of SM. They believe that SM reduces the isolation of patients and carers, but it is not sufficient for patients, and they still need a face-to-face connection or physical contacts. So SM is seen as an enabler, but further non-SM communications and contact are also needed. So overall, SM facilitates communication for enabling co-production.

The second group, charities and voluntary organisations, use SM more than the first group. First of all, SM is mainly used for advertising and broadcasting health information. The other main use of SM for these organisations is fundraising or organising campaigns. I observed that SM is used for collaboration with other organisations through sharing of information or advertisements for health purposes, which is a type of co-delivery of service. As the literature shows, SM has the potential to reduce cost and resources, but I showed that these organisations do not use SM (e.g. FBGs or Forums) due to lack of resources. The majority of these organisations use web 1.0 for their work. Some use blogs for sharing information or stories on their websites. They seek to control content published by patients and carers to avoid distribution of incorrect information, and this is a costly issue. These organisations seek to use a template for encouraging their patients and carers to publish their stories voluntarily, with charity organisations also highlighting that access to the right information and groups by their patients is a challenge in the use of SM.

The final group, informal carers and patients, use SM for a wide range of activities. The findings show that SM reduces the isolation of carers and patients by connecting those with similar conditions. Furthermore, by sharing knowledge, experience and receiving feedback from other people with the same condition, SM enables co-delivery of services. Through SM, patients and carers can share and receive emotional support from other patients and carers. In some cases, comments from others inspire confidence in dealing with problems. SM can be a solution to their fear of the outside world. Different SM have different levels of intensity and effectiveness on their users. For instance, blogging is effective for long-term investment and sharing of detailed experiences while micro-blogging (Twitter) is seen as a convenient platform for

reaching a large number of professional individuals online, or for attracting attention and calling for collaboration in different events.

For use of SM by this group of people, a number of challenges exist. They range from not having enough self-confidence or knowledge to start using SM (for instance to write a Blog), or the possibility of a conflict in feelings, lack of understanding or even disagreement when SM is used.

Chapter 5 focussed on the question of how current SM can lead to co-delivery of new services. In this chapter, I showed that SM leads to the creation of new services by enabling co-delivery of health and care. I used Cohen's four principles of co-production (equality, diversity, accessibility, and reciprocity) to show how co-production (co-delivery) is enabled through SM. SM enable **equality** through allowing recognition of experiences, skills and abilities of users and providing a platform to share assets as valuable resources. It also removes the culture of "us and them" by proving a flat administration with respect to volunteers rather than hierarchies of control. SM also enables **diversity** by being inclusive of under-represented people as well as by connecting diverse groups of individuals. SM increases the ability of open discussions by patients and carers without the need of face-to-face connection, and therefore it removes some of the psychological barriers. Additionally, SM makes groups' experience **accessible** for patients and carers by removing barriers relating to distance. In this regard, SM provides a platform for sustaining long-term discussions and fast exchange of knowledge. Furthermore, SM supports **reciprocity** by encouraging mutual sharing of knowledge and mental support. SM encourages users to give and receive support by sharing knowledge and experiences or emotional support. The sympathy that comes from patients with similar health conditions has the potential to create a positive relationship between different users.

In health and care, different groups of actors often have conflicting values or goals. Technology, especially SM, can bring those groups into contact with each other. This new form of communication channels makes some of the conflict more apparent. For instance, in most health and care systems, there are conflicts between social care and health professionals, such that social carers tend to lose in this competition because of the power of the medical lobby. Use of SM can shed light on these conflicts.

Despite the many enabling factors of SM, it may also lead to new forms of conflicts and competition for services. For instance, on the one hand, for those with low technology literacy or those in areas with limited internet connection, there is a challenge in accessing the same services as other patients and carers who are technology savvy and who are in other areas of the country. On the other hand, empowering patients and carers by enabling the sharing of knowledge and allowing for better communication has several consequences. Firstly, this can lead to the distribution of inaccurate or harmful information, which calls for some type of content control. Secondly, if patients and carers acquire new knowledge, this may lead to conflicts between patients and professionals in reducing patients' trust as well as potentially licensing them to disregard (parts of) the advice of professionals. On a different note, the use of SM can lead to other unintended negative consequences such as a fall in movement and face-to-face activities or focusing too much on the negative comments of others.

So, whilst I showed that SM can enable co-delivery of health and care, I also showed that the new conflicts and competitions resulting from the use of SM requires better management to enhance the coordination of the CPR.

Social Media in Health and Care Co-production

Name	Status of app or programme	Users			Coordination goal
		Professional carers	Carers	Patients	
Year Zero					
A better plan	Stopped working	X		X	A care planning application designed to help health and care professionals and patients to collaboratively consider and set a range of health, wellbeing and personal goals.
Good Neighbours	Stopped working	X	X		A social networking application that allows users to create circles of support with family members, friends and carers and to share and allocate tasks and diaries within an online social support network.
No Delay	Stopped working				An application that allows GPs to prescribe a digital postcard.
e-Redbook	Functional		X		A digital version of Redbook that logs a child's health and care information such as developmental growth and milestones, vaccinations, and other information from birth.
LiU					
LiU	Changed		X	X	A portal acting as a single access points to the range of services offered by LiU.
Flourish	Changed		X	X	A suite of interactive tools to support self-management of long-term conditions experience guides', NHS resources, a home monitoring service and a text messaging service.
Shine	No longer exists		X		An online profiling service to identify individuals' skills and expertise along with encouraging members to help others to share their own skills and "talents" in their communities.
Connect	Merged with My Condition My Life		X	X	A means for people to remain 'connected' with their friends, family and caregivers via Skype or the Cisco Jabber Client video conferencing suite.
Discover	Merged with ALISS	X	X	X	An online portal with access to information on a range of health and social care products and services available in local communities.
Other Sub-programmes					
More Independent (MI)	Stopped working		X	X	MI offers a wide range of ways to increase independence, some of which are aimed at those with health needs. But it is also suitable for people who are looking ahead and planning the next stage of their lives.
i-focus	Stopped working				An overarching DALLAS community, consisting of three workstreams aimed at fostering technical and strategic coherence, cross-sector collaboration, consumer-focused innovation and real commercial scale to the DALLAS programme.
Independent Application					
Our Big Box	Stopped working	X	X	X	A memory reminder application for people with Alzheimer's to remind their family of their condition.
Healthunlocked	Functional	X	X	X	A group of health and care online communities for wide range of health and care and wellbeing conditions.
Babylon Health	Functional	X		X	A health service provider for virtual consultations with doctors and health care professionals via text and video messaging through its mobile application.
Jointly	Functional		X	X	A mobile app for a patients or informal carers to schedule and share care activities.

Table 8-1- New health and care applications and programmes

Chapter 6 focussed on the questions “How can SM be reshaped to make possible co-delivery of services?” and “How can SM be reshaped to make possible co-delivery of new services and improve integration of health and care services?”- In this chapter, I showed how new SM (new health and care applications developed for health and care services including SM concepts) help to enable co-service (co-production) during the reshaping of health and social care in the UK. Initially, I reviewed a number of SMs, the results of which are presented in the Table 8-1. The results show that a large number of conflicts (e.g. competition for access to informal carers and voluntary and charity organisations) are addressed by SM.

I showed that SM can support co-design (by allowing all actors to be involved in the design of services, hence making the service fit for purpose), co-delivery (by changing the details of interaction, which in turn leads to the more economic use of services), and co-governance (by changing how services respond to changes). Through SM, individuals can change the way service delivery works. However, at the same time, co-production activities have associated costs, require a change of culture, and increase the need for time dedicated by different actors. There are also data security and protection and data accuracy and validation issues surrounding the use of SM applications. All of these matters are challenging. However, the benefits gained through the use of SM outweigh the costs involved. The findings also point to the claim that many of the health and care-specific SMs supported by government initiative have used unsustainable funding mechanisms and therefore they have terminated or transformed to other programmes after the initial phases of funding are spent. This is different to the applications developed by the private sector.

Chapter 7- In this chapter (Application framework – Carer Board System), I used a different lens to analyse my findings. Here, I presented some challenging scenarios faced by carers or patients and highlighted that lack of coordination, proper communication, trust, integration into practice, training, cultural and institutional change, data security and authority, and access to relevant information have a significant impact upon many of these issues. I then offered a set of mechanisms required in response to these challenges. They include the formation of the circle of

care, templating, time bank, skill bank, expertise bank, and matchmaking. I then showed that many of these issues could be solved by means of minor tweaks and a redesign of the use of current or new SMs, rather than the development of new applications. I showed how existing applications can provide a communication channel and support coordination across existing (formal and informal) health and care resources. I concluded by showing that the adoption of this approach requires special consideration in terms of ownership of both application and data.

Therefore, to summarise, a range of conflict that arise through the use of SM in health and care (as identified in different chapters of this thesis) are:

- Use of SM may lead to access conflicts where some group achieves better access because of their better use of SM. For instance, there is a gap between older and younger generations in relation to use of technology, which may result in differing levels of access to some resources.
- SM use can lead to changes in the balance of power between different patient groups. For example, different patient groups may be formed for lobbying for better treatment for a specific condition.
- SM use can lead to changes in the balance of power between patients and carers and health professionals. There is a conflict of perspective (professional and patient) on knowledge distributed via SM. Professionals look for scientific evidence, whereas patients identify social evidence. This leads to the push from patients to become involved in decision-making processes.
- SMs bring groups together that might not otherwise interact. These groups may have conflicts, but they tend also to have existing mechanisms to manage that. SM upsets this balance by introducing a new channel. This can lead to issues such as conflict of feelings in response to other patient's posts, disagreement, free riders, and the increase of internet trolls.
- SM makes news/knowledge more transparent without any control by authorities and professionals. This may lead to fear or loss of trust in professionals
- Knowledge-sharing may lead to propagation of inaccurate or harmful information.

- There is a risk of the spread and application of knowledge without understanding the context (e.g. the particularities of a patient's condition).
- Use of SM can also lead to a number of data challenges, such as data security, breach of patient privacy, loss of patients' information protections and problems with respect to data accuracy and validation
- Increased use of SM can lead to new forms of loneliness and separation from society. It can lead to less physical activity.
- Due to the need for some level of control on the content that is shared, organisational costs may increase as a result of new applications of SM.

This list is not comprehensive. However, it shows that use of SM as an enabler of co-production (as discussed in each chapter) may also lead to new forms of conflict that require attention.

8.3 Theoretical contributions

In this research, I have observed a multitude of links, interrelations and consequences between humans (users of SM), technology and organisations (e.g. NHS, charities, professional care organisations). This is consistent with the overall sociotechnical approach used within this thesis. NPT as a 'middle-range theory' of sociotechnical change (May et al., 2007) allowed me to explore the mechanisms adopted by patients, carers, professionals and organisations for the embedding of SM in providing and receiving health and care services, whilst also showing the consequences of use (positive and negative) on other people, organisations and technology. I observed that there is a changing and growing landscape with respect to adoption as SM is normalised in the lives and work of users.

May et al. (2018) explain the different ways that NPT theory's constructs can be integrated in different research methods. In my research, I translated the contents of the theory into practical research questions used within a flexible framework, allowing for an adaptable data collection technique. This allowed me to start with a deductive data collection process and move onto a more flexible questioning as new themes emerged whilst the data were analysed inductively (May et al., 2018, Tazzyman et al., 2017). So, as I was looking for actual uses and new opportunities in use of SM for co-production of health and care services, this theory-led analysis, which did not force

data into a rigid theoretical framework (Tazzyman et al., 2017), served as a practical tool for conducting this research.

As a result of this approach, this study contributes to two main fields. Initially, the study contributes to the growing body of research on co-production in health and care. This dissertation also contributes to the studies around SM and their applications and impacts on the health and care sector.

8.3.1 CPR and co-production in health and care

The initial contribution of this study is the application of the notion of common-pool resources (CPR) in the management of health and care resources. CPR is well defined by Elinor Ostrom, who explains the ways in which common natural resources (such as water, fisheries, and rangelands) can be communally managed in a sustainable way. Ostrom (1998) also hints that CPR theory has possible applications for man-made common resources. In this study, I suggested that health and care resources (including professionals, formal and carers, local communities and charity organisations) can be seen as a common pool of resources, accompanied by a large number of conflicts and competitions. I then investigated how co-production, through the use of SM, is used for management of CPR (in particular the large pool of informal carers). In doing so, I highlighted the conflicts and competition for reaching resources and then showed how SM can help to overcome some of the conflicts identified.

In using the concept of co-production, I looked into its four main aspects (co-design, co-commission, co-delivery, and co-assessment), but I focused more deeply on co-delivery, touching on some aspects of co-design of services.

Through the concept of co-delivery, I showed how different actors (in particular informal carers) can be communally managed, how their actions can be coordinated with the actions of other actors, and how consensus can be achieved to deliver services required by elderly patients. Co-delivery also covers the engagement of patients in the delivery of services. This serves for the increasing calls for self-care and self-management in health and care services. In this study, I observed how SM can be used to form a dynamic and effective partnership between patients and other actors for better self-management. I used Cahn's framework in order to explain how co-

production is set into action, but I also went beyond that, explaining that conflicts and competitions (which are key factors in CPR) may be resolved to a certain extent through the use of SM, but they are not yet fully settled. This corroborates the findings of studies concerned with the inability of some patients to be engaged in co-production activities and the resulting lack of ability to benefit from co-production, due to poor health (Ewert and Evers, 2014, Vennik et al., 2016).

Governments draw attention to the importance of partnerships between professionals and beneficiaries (patients and carers) in co-producing public services (Radnor et al., 2014, Alford and Yates, 2016, Pestoff, 2009, Osborne et al., 2015, Bovaird et al., 2016, Pestoff et al., 2006). I identify several benefits achieved through this move: (1) making use of the expertise of service users; (2) facilitating the introduction of more differentiated services; (3) a growing response to the dynamic needs of service users; (4) decreasing costs and unwanted outcomes. My study shows how SM can facilitate these benefits by engaging different beneficiaries to help to deliver existing and new services and to respond to some of the needs of the patients in a more efficient way. However, it also goes one step further and shows that, although some challenges are resolved, some other challenges have only changed in terms of their nature. More importantly, I show that SM may also result in the conflicts being shifted in terms of their origin, or it may change the nature of the conflicts or the extent of their effects. Moreover, whilst some competition may be fully resolved by SM, some new conflicts may also be given rise to.

There are some preliminary findings around co-design (which call for follow up studies). Many initiatives have begun, and investments have been made, to enable co-design. However, the design process has proved to be very complex around co-production. Co-design projects (including workshops, meetings, etc.) can be very expensive and they require a large number of resources to be involved in the process. However, maintaining the engagement of resources in the lifetime of a system has proven to be challenging. Initial investments for bringing together resources have been conducted, but after the early funds are spent, there is no mechanism to keep the resources engaged for the long-time span of the product beyond the scope of the

project. This is why many projects have not sustained far beyond the end of their duration. For instance, LiU project (part of the DALLAS project) used co-design for designing the new services. Initially, this seemed to be a successful project that delivered on its design goal. However when the project budget was spent, and the outcomes were taken over by the NHS, many of the services (or some of their parts) were terminated without having achieved their intended goals. Similarly, many DALLAS projects (such as GoodNeighbour, NoDelay, ABetterPlan) and some projects Funded by the AAL Programme (Active and Assistance Living Programme) were terminated.

Co-production in the health and care sector has also faced another challenge, which I refer to as ‘scaling up’. There is an argument that we should have one integrated health and care system which leads to better outcomes. However, the counter argument is that, as systems grow bigger in scale, the level of co-productive involvement goes down. This is because scaling up leads to an inability to quantify people’s efforts and inputs into the system, which in turn leads to loss of co-productive ownership by society (patients and informal carers). So, by looking at the different initiatives, I observed that the co-productive efforts worked better on small scale projects (e.g. MyDiabetesMyWay) where there was an element of locality and, as a result, resources continued to support the system.

Another conflict resulting from the co-production initiative is the extent of innovation and how it is perceived by different actors. I observed that, in cases where new developments took place to provide a tool for better delivery of existing services (such as eRedbook), the co-production outcomes are more sustainable than when new services are offered by co-production. One reason for this is that sometimes new services led to new competition and conflicts of interests. For instance, some services offered by LiU led to change of power relationships and authority, which was not welcomed by some of the stakeholders. This resulted in the termination of many projects (e.g. LiU, ABetterPlan, GoodNeighbour), which were considered successful for a short period of time.

8.3.2 Studies of social media

The findings of this research contribute to the field of the study of SM in several ways. Due to the complexity of settings and the interrelations and bidirectional consequences of actions, acts and tools, I do not classify these contributions into the typical technical, social and organisational aspects delineated by the sociotechnical approach. Instead, I classify them into the following themes:

- **Information reliability:** My findings confirm that SM can be used to enhance communication in the health and care sector (Moorhead et al., 2013, Egan and Moreno, 2011b, Lord et al., 2011, Rolls et al., 2016). However, there are sometimes issues pertaining to the quality and reliability of discussions on SM (Adams, 2010b, Adams, 2010a, Friedman et al., 2011, Hughes et al., 2009, Kim, 2009, Moen et al., 2009, Nordqvist et al., 2009, Orizio et al., 2010). My findings expand this by showing that in new purpose-built SM, where patients or carers are located in a place with someone with similar conditions, users report improved quality of information. And the use of control (by organisations and patients) can improve the quality of data shared. Furthermore, my findings show that health professionals are hesitant about the use of SM information by patients as they are concerned about the reliability of data produced online by non-professional users. I show that involving professionals in co-design can reduce this concern.
- **Resource identification and management:** The literature shows that, in general, SM enables better distribution of information as a resource for health and care purposes (Kim et al., 2014, Denecke and Nejdli, 2009, Hu and Sundar, 2010, Sanford, 2010, Tian, 2010, Rajagopalan et al., 2011, Nordqvist et al., 2009, Kim and Kwon, 2010, Wicks et al., 2010, Liang and Scammon, 2011, Dieleman and Duncan, 2013). My study adds to this by presenting that SM makes visible various types of health and care resources (such as the availability of carers, care programmes, symptoms and cures, communication techniques, etc.) to meet the needs of elderly patients. My research also presents ways in which SM can be used as a means of managing health and care resources (e.g. Trello as a co-ordinating tool).

- **Empowerment:** There is a large body of studies around the use of SM for health and care communication (Moorhead et al., 2013, Egan and Moreno, 2011b, Lord et al., 2011, Rolls et al., 2016). I show that, by facilitating new modes of dialogue between different actors (i.e. patient-patient, patient-carer, carer-carer, patient-professionals, and patient-health and care organisation), SM empowers users (in particular patients and carers) by providing them with a tool for faster and more effective modes of social interaction. This empowerment results in better management of self condition on the one hand, and more effective knowledge-rich communication with professionals on the other.
- **Costs:** Many studies of SM claim that SM can reduce costs (Chew and Eysenbach, 2010, Jennings et al., 2009, Scamfeld et al., 2010, Scotch et al., 2008, Signorini et al., 2011, Weitzman et al., 2011). Whilst my findings confirm this in some respects, I also show that, in some situations, new costs are introduced through the use of SM. For instance, in voluntarily organisations, for controlling the contents produced on SM, new resources are needed.
- **Usability:** My findings are consistent with the general SM literature showing that usability problems can lead to barriers of adoption (Househ et al., 2014). Patients and carers encounter difficulty in the use of social media, particularly older users. The literature suggests that collaboration in the design of ICT applications can enhance usability (Eason, 2007). My study shows that co-design provides a means of achieving this. However, co-design may have other consequences once the project funding is spent and applications are put into use.
- **Data Privacy:** The literature also evinces concerns in terms of data privacy and data confidentiality (Househ et al., 2014, Lober and Flowers, 2011). My findings add to this literature in showing that purpose-built SM can streamline some of these challenges by providing control specific to health and care of content and boundaries for exchange.

- Differing purposes: There is a need to understand the various uses of SM by different groups of actors (Antheunis et al., 2013). My findings respond to this need by showing how different stakeholder use SM for different overall aims. For example, patients tend to use SM for emotional support and the source of complementary knowledge. Carers use SM as a tool for coordination and clinicians utilise SM's information carrying capacity.
- Differing tools: My findings also point to the diversity of tools used to achieve different purposes. For instance, private FBGs and forums are most widely used by patients with similar conditions and their carers. The main difference is that forums are mainly sponsored (and administered) by communities and charity organisations, which allows for better control of data. Micro-blogging (e.g. Twitter) is used both by professionals (e.g. doctors) and non-professionals (patients) due to its 'flat' and 'fast' nature (allowing rapid exchange of information based on users' interest in topics) and charities and organisations who wish to attract communities of interest or funds. Blogging, on the other hand, is used for slow but detailed sharing of stories by people and organisations about their health interests and experiences. By analysing the nature of each application and its current uses, I identify several characteristics which are needed by patients and carers in order to coproduce health and care:
 - Privacy of closed groups and Forums is needed while they provide easy accessibility and equality;
 - Speed and diversity of Twitter;
 - The sharing of experience on blogs makes knowledge accessible;
 - Promoting events and health information in a rapid and widely-distributed manner;
 - Bringing together carers, professionals and patients;
 - Encouraging long-term mutual support.

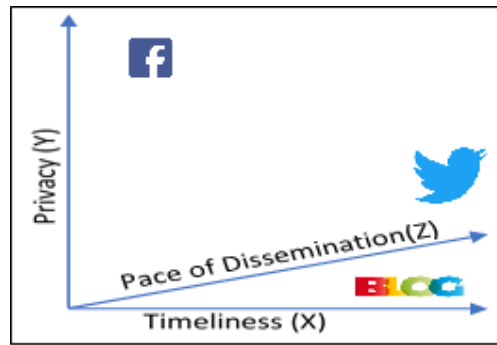


Figure 8-1 - Specification of social media

I classify these characteristics in a three-dimensional model (Figure 8-1), which shows that there is a need for diversity in terms of privacy, pace of data dissemination and timeliness of information use. I have added some example applications to illustrate some possible options. Privacy, on the Y axis, relates to the fact that, for different purposes, differing levels of privacy are needed. For instance, for quick updates on health discovery, Twitter would provide sufficient but not extensive privacy, whereas for discussions about one's particular condition, closed FBG groups or forums require greater levels of privacy and data sharing controls. Timeliness, on the X-axis, refers to the short or long-term effectiveness of information shared for the audience. For example, blogs may produce long-lasting information about management of a condition. In other words, a large amount of data on blogs is used and remains effective for a long time, whereas data shared on Twitter is typically intended for immediate use. Finally, the pace of dissemination refers to the speed of dissemination of data on different SMs. Whilst Twitter offers fast and rapid dissemination, blogs are usually slow in terms of dissemination but more in-depth in use (timeliness).

There is not an ideal point on this figure. An ideal application should offer various functionalities that map on various points of this figure to cater for the various needs of different individuals. So, as explained above, there should be Twitter-like function for fast and short dissemination to large public audience, as well as FBG-like functions for private or more in-depth communications. The model is intended to demonstrate that there are various options and various needs that need to be considered in the designing of applications.

I conclude that different levels of co-production are enabled through SM use by different stakeholders relating to health and care. I also found tensions in the use of

such systems. These findings have implications for broader thinking about co-production for health and care and how SM can act as an enabler in relation to this field. Traditional understanding of SM use for health and care may need to be re-conceptualised to incorporate a more nuanced perspective on various aspects of co-production (i.e. co-commission, co-design, co-delivery, and co-assessment). This should also involve re-modelling different uses for different purposes, different actors and different practices.

8.4 The implications for policy and practice

The findings of this research show that neither the developers nor the adopting users or the policymakers were prepared (individually, organisationally, technically, and legally) for the scale and complexities of co-design and co-delivery. This is reminiscent of many other technological investments in the health sector (Robertson et al., 2011, Sheikh et al., 2011, Mozaffar et al., 2015). My research points to a range of implications and recommendations for policy and practice to address and overcome some of these challenges.

8.4.1 The sustainability of innovations

My findings conclude that investment into the co-production of health and care through technology may be construed as giving rise to a range of relatively unfinished innovations into the field. In the process of investment and planning for many SM projects, the sustainability of innovations was not considered as a central subject matter. This suggests a need for a sustainable move in policy investments. Continuous planning for support in the use, optimisation and maintenance beyond system design and development is needed to achieve this, this research having found that some of the applications (which received government funding) terminated after several years of use (or even less). My research shows that one of the outstanding reasons for the failure of continuity of many of these initiatives has related to completion of a project without having clear support and plans for use and ownership after the go-live period. Many projects are underfunded as they run out of funding before they are fully imbedded for longer-term use. Therefore, to overcome this issue, policymakers and funders of such projects require to formulate clear follow-up plans. The sustainability of health and

care is a difficult issue and there is a need to build more sustainable apps that have reduced maintenance costs relative to current methods.

8.4.2 Combining top-down and bottom-up approaches

The research proposes that, rather than trying to solve all of the problems at once, gradual and piecemeal solutions that have the support of public and patients for co-design and co-management are a way to overcome some of the challenges. This will allow for a sustained user engagement (Cresswell et al., 2017) throughout system design and use. In general, enabling co-production calls for central guidance or a framework to be provided by the government, but more importantly, users require to be involved through co-design and co-delivery of services. My findings show that whilst some top-down initiatives (e.g. eRedBook) have achieved their primary goals and are now expanding, in many cases bottom-up approaches are the key to sustainable products. As a result, many projects require to start locally and function at a local level before being transferred to other settings. This has several benefits, including ironing-out early problems before attempting wider roll-outs (Cresswell, 2012) and retaining support without loss of interest.

Additionally, there tends to be a poor understanding of governance issues. For instance, there is limited acknowledgement relating to the adequate management interfaces. Moreover, many technologies are driven by a lone consumer model, such as fitness watches. However, the health systems are concerned with governance at a population level. So, there is a need for better understanding of how products scale beyond a local context.

8.4.3 Re-purposing innovations

The findings of my research also suggest that instead of investing in many new initiatives, funders need to focus some of their investment on re-purposing and expanding existing innovations to cater to the wide range of needs of the patient and carers. More effective mechanisms can be deployed to bridge the gap between innovations and needs. Policymakers and practitioners need to spend time and effort in better management and enhancing the use of the designed applications for providing health and care services (both existing and new) rather than spending resources on reinventing the wheel. Moreover, the repurposing of many existing SMs (with minor

changes) with a focus on the mechanisms explained in Chapter 7 can enable the co-production of health and care.

8.4.4 Measuring effectiveness of innovations

My findings also highlight that a large number of innovations are happening around SM applications for health and care purposes. However, despite the large number of SM innovations in this field, their effectiveness is not measured and their outcomes are therefore not evaluated. As Nigel Edwards (Samer Faraj @samerfaraj, 18 June 2018, 3:35 PM, Tweet) said in a digital health forum, “there are upward [of] 150 asthma management applications available, but we have no idea about their effectiveness [in relation to] digital health”.

8.4.5 Organisational readiness

There are also many issues relating to the readiness of the adopting organisations. These issues range from user organisations not having a clear understanding of how to decide to adopt a technology, to unwillingness or unawareness on the part of individuals within the organisations to cooperate in the implementation and use of technology. Organisational and individual awareness, change management, and training programmes require to be introduced to enhance organisational readiness.

Additionally, my findings point to lack of long-term strategies adopted by charities in the use of SM. My work indicates that a long-term model of SM adoption and use is needed such that it foregrounds the potential opportunities and concerns of different users and pursues different strategies and financial plans to be considered over time.

8.4.6 Balancing visions

My research clearly highlights that different stakeholders have different objectives and values in the use of SM for health and care. Some stakeholders seek sharing of feelings, some focus on improving the delivery of healthcare services, some on the cost effectiveness of services, and some on improving the quality of care outcomes. Aligning (not streamlining) these different views, where possible, provides a way of overcoming some of the challenges caused by these diverse interests. In order to achieve this, different visions require to be identified and acknowledged, and relationships require to be built to improve communication channels between various

actors. Different strategies, such as the creation of user communities, need to be put in place to achieve a better understanding of the care ecosystem (including informal care), the role and needs of different organisations, and the creation of integrity across settings.

8.4.7 Managing professional resistance and the reconfiguration of roles

Policymakers have realised that, to provide better and more efficient health and care services, the health and care system requires to be redesigned. However, health professionals do not necessarily agree that the health and care system is in need of reform or, more specifically, that the area of the health and care with which they are concerned requires to be reformed. They may not agree on what the new service should look like or how it should work. Research shows that both new and existing SM are able to bring many benefits for society and they can lead to reduction in both cost and effort by the NHS (Scanfeld et al., 2010, Signorini et al., 2011, Weitzman et al., 2011). However, health professionals require to respond to the changes brought on by SM. SM can lead to a change in power dynamics and the everyday work practices of professionals. This reconfiguration of roles needs to be managed through paying closer attention to professionals' planning, training and education (Stead et al., 2011, Fraher et al., 2013). Due to the large scale of the NHS, and the tension resulting from top-down funding and the need for bottom-up change, restructuring of the services requires formal planning to allow for more effective reconfiguration of work practices.

8.5 Research strength and limitation

The research has a number of strengths and limitations. First, this research was conducted during a time of health and care redesign in the UK (specifically, in Scotland). During this time, the Scottish government approved plans to use the concept of co-production in the reform of the system. This can be viewed as a strength as it helped me to contextualise my work as it was happening and it was discussed widely by the surrounding community. However, the specifics of this timing meant that I could not take into consideration a long-term perspective and the associated consequences. This requires to be addressed through future study.

Secondly, during the time of the research, the DALLAS project was being carried out. This gave me a very good opportunity to collect data on the project (and a number of its sub-programmes) as it was happening. I also followed up on the outputs of the sub-programmes once the funding period was over, and observed how a number of sub-projects had stopped while many others were taken up by other organisations. While this was very useful in relation to facilitating an understanding of the fate of such digital health and care programmes, the downside was that the change of people who were involved at the earlier time of my project led to restricted access to the new teams. This was even more problematic for the projects which were terminated, as I could not fully follow up on the reasons for termination. I therefore found myself analysing data by implicitly thinking about it as a “success” or “failure”. To move away from this signposting, and through my qualitative approach, I sought to go in depth to explore the more subtle underlying conflicts and tensions that had resulted from these various outcomes.

Furthermore, I drew on NPT, which served as a socio-technical analytical lens to help gather data on the benefits as well as the challenges of various types of SM and their applications in relation to health and care. This approach gave me a systematic tool to collect data around various aspects of my research aim. A limitation of this approach, however, was that it did not identify the long-term consequences of the benefits.

I have drawn data from multiple sources, including patients, carers and charity organisations, to enhance confidence in the findings and ensure the presence of diverse perspectives. However, due to the sensitivity of patient data, I only had limited access to private FBGs and Forums (I contacted several groups and gained access to one particular group). To include perspectives from participants in other groups, I conducted further interviews with patients and carers who were members of several other FBGs and Forums. During the course of this study, I came across a secondary source of valid data, which had the ability to strengthen my finding. I therefore used an opportunistic approach to broaden my research to include patient perspectives. In particular, as I had limited interview data from patients, this source coming from research on patient self-management allowed me to strengthen my findings.

An additional challenge in study of technology is the fast-changing nature of what is under investigation. In particular, in the case of social media, the evolving nature of the tools and creation of new tools means that any research done within this field will typically become outdated very quickly. Despite this, I sought to maintain a lookout for new developments during the course of my study. In particular, I looked out for health and care SM tools.

There also some conceptual challenges due to the complexities of the health and care settings and the time limitation of a PhD project. This required some simplification of the situation on my part. I therefore narrowed down the scope of the project to particular perspectives. This meant that the views of some individuals (i.e. policymakers and NHS professionals) are not considered here. I therefore acknowledge that my findings are not necessarily complete, and they represent a particular time and particular perspectives. Yet, the results are consistent with previous literature on SM, pointing to likely transferability to other settings.

Being aware of the limitations discussed above and taking the opportunities to strengthen the work in other ways (as mentioned above), I presented my findings in a coherent way. Throughout this process, I questioned my assumptions and discussed my emerging findings with others conducting research in the field (including my supervisor and a community of health informaticians). This ongoing process helped with achieving confirmability and credibility in relation to my study.

8.6 Recommendation for future work

In using the concept of co-production, in this work I focus on the co-delivery of services. My work also highlights some aspect of co-design and its importance and opportunities in co-production of health and care services. This work could be expanded to focus more deeply on co-design (through involvement of different stakeholders), as well as co-commissioning and co-assessment of services.

The theoretical models developed during the course of my study (e.g. figure 8-3) need to be tested and evaluated in other SM contexts. This may lead to identification of particular ideal points for particular purposes. This will also test whether the models need to be modified or expanded.

Additionally, this study was carried out in several instances of project times. Therefore, more longitudinal work investigating existing and new SM for health and care purposes is needed to identify the long-term outcomes and consequences. This will allow the gathering of deeper insights into the way innovations become embedded into the practices of individuals and organisations. This work might include detailed process mapping in relation to the use of new SM by different actors (such as formal and informal carers and professionals). My current findings point to the creation of new services as well as changes in existing services. Therefore, deep, longitudinal, and cross-organisational insights are needed to identify the long-term consequences of these technologies. In line with this, it is also necessary to understand the changing needs of the health and care sector.

From an empirical perspective, although this work has provided some important insights, there are also a number of limitations. Firstly, I did not seek the perspective of NHS professionals, such as doctors. This can be addressed in future research with a focus on professionals. Secondly, in this research, I have focused on users of SM. This leaves open the question of what happens to the population who do not use SM. Further studies therefore require to be conducted on non-users. A further challenge is that this research focused on the work of informal carers and voluntary organisations, and so further work is required to understand the perspective of social workers.

Finally, in Chapter 7, I propose a possible SM model which can be used as a coordination tool between patients, formal carers, informal carers, and professionals. This model needs to be implemented and tested to identify any associated gaps and potential for expansion into actual settings.

8.7 Conclusion

This work began as a study of investigation of SM as an enabler of co-production in health and care for elderly people. My focus was on co-delivery of services, with particular attention being paid to patients, (formal and informal) carers, and charity organisations. In this work, I developed a typology of opportunities and limitations of SM for health and care, which involved looking into existing and new SM for the delivery of existing and new services. The national DALLAS programme provided a unique opportunity to study these settings as new technologies were forming. At the

same time, the Scottish health and care reform initiatives allowed me to study this context as relevant change was taking place.

Based on the findings of my research, SM can be seen as an enabler of co-production by offering mechanisms for coordination of the common pool of carer resources. However, the analysis also shows that many technological innovations in this field have not been sustainable, have not met their intended goals, or they have not been used to their full potential.

Overall, despite the associated challenges and new forms of conflicts and completions that may result from the design of new SM applications and use of existing SM for health and care purposes, these efforts should be viewed as a valuable learning experience for all involved. The achievements, struggles, and abrupt terminations provide important insights into a long journey for the reform of health and care services.

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Appendix 1 - The context of age

Encyclopaedia of Population has a definition for older people as “the aging of population often is measured by increases in the percentage of people in the retirement ages. The definition of retirement ages varies, but a typical lower cut off number is 65 years. A society is considered relatively old when the proportion of the population age 65 and over exceeds 8 to 10 present” (Demeny et al., 2003). This is the age that most people will be retired (There are plans to increase the retirement age by 2 years). So, I can say older, elderly or aged people are those who are spending their retired period of life.

The aging population

United Nation published statistics that shows the world is facing with a huge increase in number of aged people. The number of older people (65+) is projected to increase nearly triple times, from an estimated 524 million in 2010, (8% of the world’s population), to nearly 1.5 billion in 2050 (**Error! Reference source not found.**), (representing 16% of the population of the world)(Organization, 2015, World-Health-Organization, 2011). The oldest people are in more developed countries while the most rapid growth of older people is happening in developing countries.

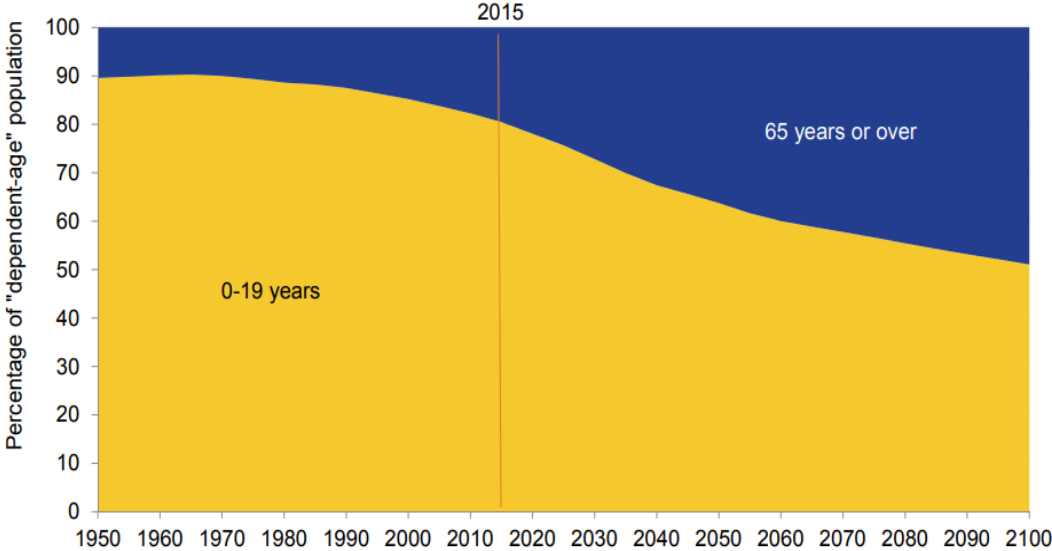


Figure 1-1- Children and young people aged under 20 and older person aged 65+ as a percentage of the global population – (Source: World Population Prospects)

The proportion of older people in Europe was 14.7% in 2000. In the past the highest proportions were found in Northern Europe (e.g., 10.3% in Sweden in 1950²), but by 2000 the highest population of elderly were in Southern Europe (e.g., 18.1% in Italy). The UK is facing a similar trend in rise of aged population (see **Error! Reference source not found.**) (Demeny et al., 2003). There are 10.3 million people aged 65 and over in the UK in 2010. This shows an 80 percent increase from 1951. In 1951, 67% of aged population were between 65 and 74 years old, and only 4% were aged 85 and over. These figures have changed to 51% and 14% respectively which shows a considerable change in the age composition (National-Statistics, 2013b).

It is predicted that the UK population will increase gradually from 62.6 million in 2010, to 65 million in 2017, passing 70 million in 2028, to reach 73 million by 2035. This shows a growth rate of 17.0% in 25 years.

These trends vary in the four countries of the UK. England is projected to see 8.4% increase by 2020, Northern Ireland 6.2%, Wales 5.5 percent, and Scotland 5.1 percent. The structure of the UK population age will steadily become older. It is projected that the population of those aged 65 and over to increase by 23% from 10.3 million in 2010 to 12.7 million in 2018 and reach 16.9 million by 2035.

Ages	1985	2010	2015	2020	2025	2030	2035
0-14	10,873	10,872	11,497	12,231	12,455	12,279	12,117
15-29	13,334	12,471	12,619	12,168	12,192	12,809	13,543
30-44	11,327	12,725	12,545	13,185	14,037	14,108	13,664
45-59	9,289	12,126	13,018	13,161	12,514	12,338	12,986
60-74	8,106	9,163	9,709	10,335	10,925	11,807	11,981
75 & over	3,625	4,905	5,388	6,093	7,279	8,051	8,918
All ages	56,554	62,262	64,776	67,173	69,404	71,392	73,208
Age 65& over	8,578	10,304	11,652	12,667	13,910	15,516	16,948

*Table 1-1 – The UK Population (thousands)
(Source: Adapted from ONS 2010 – based population projections)*

Increase in aged population leads to greater numbers of elderly dependents in the future. In 2010 for every person of state pensionable age there were 3.16 persons of

² Scandinavian countries typically demonstrate more stable population structures. Even today (<https://www.populationpyramid.net/sweden/2018/>) the over 65 population is around 20% of the population but declines in fertility have been much less marked than in southern Europe.

working age. If there are no changes in State Pension Age, this number is expected to decline to around 2.9 by 2040.

Studies show that the numbers of elderly people needing care in the UK will grow by 6.6 million in the next 25 years (over 30%). Similar rates are seen in other European countries. However, the number of adults under the age of 60, is increasing by 5% only. Accordingly, the EU commission is seeking strategies, including use of ICT, for improving quality of life both in terms of health and social care while not effectively managing the costs.

Demography of health – the age pyramid

The graph of the population or pyramid/population of age in an area, such as a country or town, illustrates the change in age and sex groupings. The pyramid is divided into intervals of five to ten years and has the youngest age group at the bottom and the eldest at the top. One side of pyramid shows males while the other side shows the number of females. Population pyramids are effective in visualising changes in birth rate and death rate. (Helicon Publishing is division of RM)

Age in The UK

Error! Reference source not found. shows the pyramid of age for 25 years in the U K. In 1985 the proportion of people who were between 65 to 84 years was around 13.9% (and age over 65 years in total is 15.17%) (Wulf, 2013). With regard to **Error! Reference source not found.** the 65+ group in this year comprised 8.6 million people. It shows the gap between retirements and death was small, because people died relatively quickly after retirement.

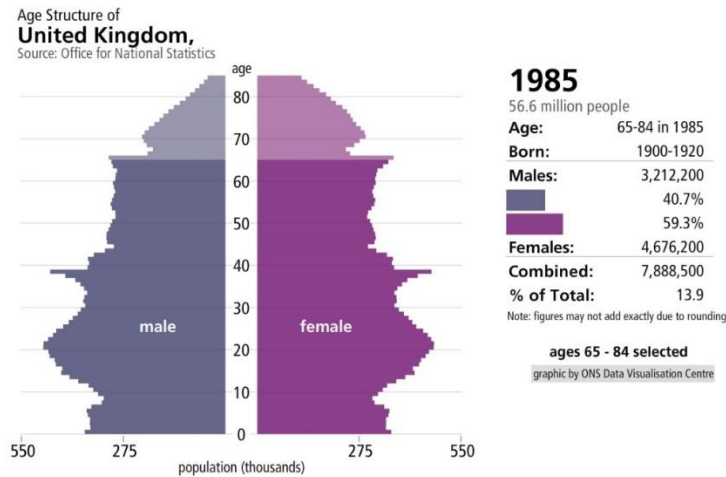


Figure 0-2- Age pyramid - the UK 1985

Error! Reference source not found. shows the population between 65 - 84 years in 2010 was 8.8 million which is 14.3% of the population in this year and compared to 1985 it has increased 0.4%. So, it shows the gap has slowly increased in the last 25 years. Furthermore, the statistic of population in 1985 shows the proportion of the target group of people (65 and over) at this time was 15.17% but in 2010 it had increased to 16.55%. It illustrates that during this time there has been a 1.38% growth.

If we look at the shape of the age pyramid we observe that the number of older people has slowly grown compared to young people. For ease of comparison, shadows in the figure show the age pyramid of 1985. As can be seen in the **Error! Reference source not found.** in 1985 the pyramid is slope from middle to the top, but in 2010 (**Error! Reference source not found.**) the slope is decreasing as people are living longer.

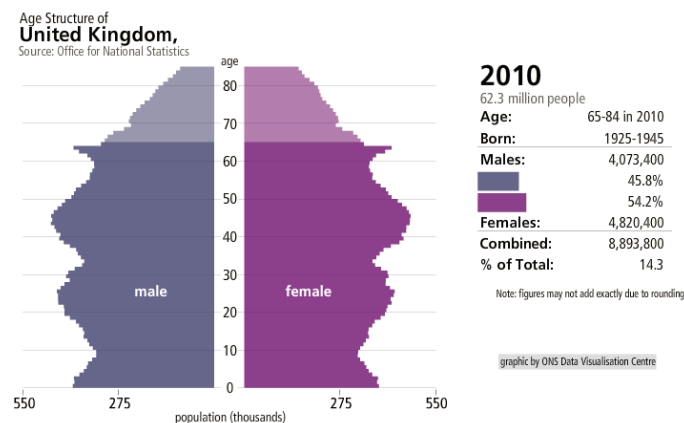


Figure 0-3 - Age Pyramid - the UK 2010

Error! Reference source not found., shows the proportion of people who work against those who do not have any job in 2013. As can be seen in the figure, almost all people aged over 65 years do not have a job. (This will be increase to 67 over the next few years). This shows a problem in earning income for the older population.

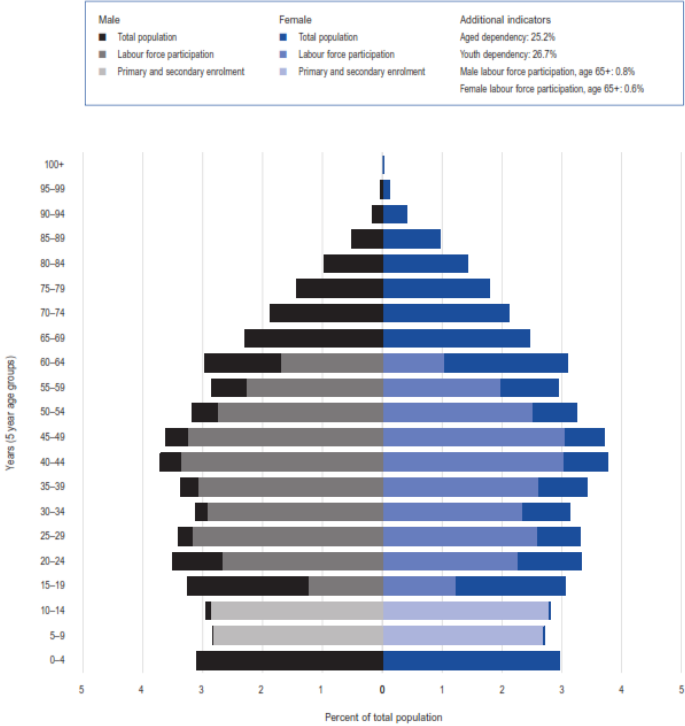


Figure 0-4 – Age and employment pyramid – The UK compared to 2013 – (Source: Schwab, 2013)

It is expected that over the next 25 years, the older population will significantly increase. According to **Error! Reference source not found.**, the target age is expected to increase to 13.45 million, which is equal to 18.4% of proportion of population. That means, in the next 25 years it will be increased by 4.1% (Between 65 to 85 year). With regard to **Error! Reference source not found.**, the population of 65+ year’s people will reach 16.95 million that shows an increase of 7% in the next 25 years. Compared to 25 years ago the growth rate has increased by more than 6 times.

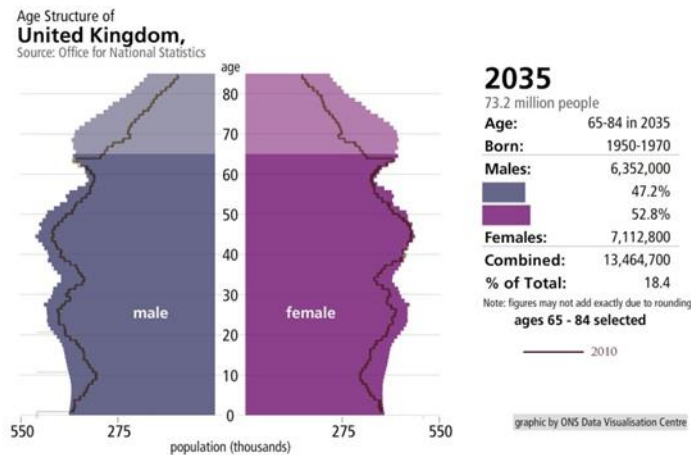


Figure 0-5- Age pyramid - the UK 2035

Furthermore, the proportion of people aged 65+ is predicted to increase in the next 25 years, it will directly affect the shape of the age pyramid, as can be seen in **Error! Reference source not found.**, the body of graph is becoming bigger in particular at the top of the pyramid which means the age of people is increasing. So, if we consider the retirement age being 65, we note that, the gap between retirement and death will grow considerably in the next 25 years. This issue will cause major problems in the future for the UK economy and society. I will return to this in more detail later. This problem is not restricted to the UK, all of the developed economies are facing a similar change in the balance between older and younger people.

The age in Scotland

We see a similar trend in Scotland. In 1985 the population of 65+ was 14.39% and it increased to 16.84% by 2010 (2.45% increase). It is expected that the percentage of people in the target age group will increase to 24.86%. This is an 8.02% increase compared to 2010. This shows a larger rise in the target age of the Scotland population compared to the UK population.

Error! Reference source not found. shows the age pyramid of Scotland in 1985, 2010, and 2035. There are two main areas of change. Firstly, on the bottom of the pyramid which has become narrower over the years. And secondly there is an expectation that the top of pyramid will observe a high increase in the next 25 years. As explained earlier this shows that the people are expected to live longer.

Ages	1985	2010	2015	2020	2025	2030	2035
0-14	998	852	868	902	907	898	880
15-29	1,260	1,036	1,034	977	956	971	1,006
30-44	997	1,036	1,017	1,067	1,125	1,107	1,051
45-59	857	1,092	1,149	1,117	1,035	1,014	1,064
60-74	710	801	851	925	983	1,040	1,017
75 & over	305	406	447	499	589	656	738
All ages	5,128	5,222	5,365	5,486	5,596	5,686	5,755
65 & over	738	879	986	1,075	1,190	1,325	1,431

Table 1-2 - Scotland's population (thousands)
 (Source: adapted from ONS 2010 – based population projections)

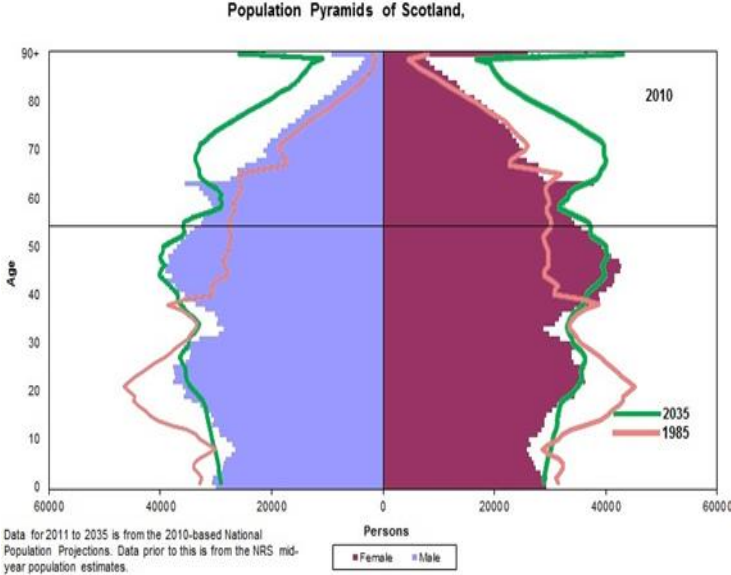


Figure 0-6 - Age pyramid - Scotland 2035

It is the most elderly age-groups of the population that are projected to increase most dramatically. Between 2010 and 2035 those aged 75 and over are projected to increase by 86%. (Error! Reference source not found.)

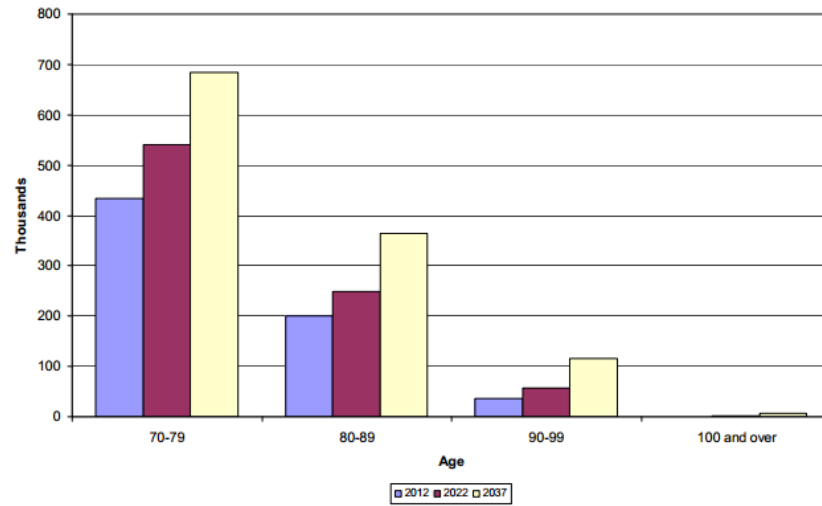


Figure 0-7- Estimated and projected population aged 70+ in Scotland, mid-2012, 2022 and mid-2037

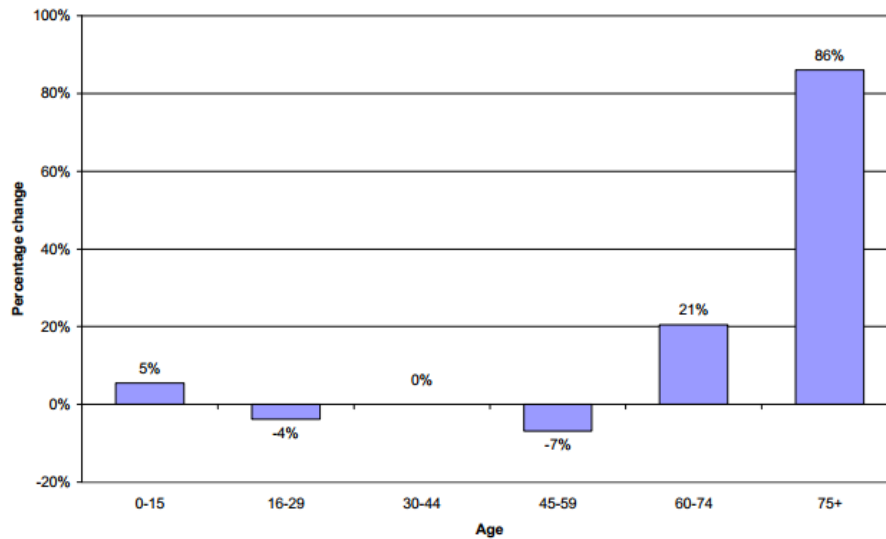


Figure 0-8 - The projected percentage change in Scotland's population by age group. 2012-2037 (Source: National-Statistics (2013b))

Healthy life expectation

Life expectancy (LE) indicates the estimated lifespan of an average person. LE is a theoretical figure rather than a prediction, because death rates could change over a person's lifetime and also people may change geographical location with different living risks. LE is usually calculated at birth but may also be estimated at other ages showing the number of further ages one is expected to live at the time of measurement. For instance, for a 65-year-old when LE is calculated (80), it is longer than LE of a new born (73). This is because their new estimate captures the fact that they have lived

for a long time and the new calculation is added to their current age (65) will generally be greater than the corresponding estimate of a baby's LE at birth.

LE only shows life expectancy and not the Healthy Life Expectancy (HLE). HLE indicates the expected 'healthy' living of a person. It is driven from combining LE and an estimate of 'healthy' health self-reported by survey showing both mental and physical health. This estimate is used to show trends in health of populations, facilitate allocation of resources and planning of services, and evaluate health outcomes (ScotPHO, 2013).

Research shows people can expect a considerable period of unhealthy living in some regions of Scotland (**Error! Reference source not found.** show this figure for Glasgow) as each individual is expected to live an average of %16.67 of their life not in good health. The figures on unhealthy LE are higher in areas with lower socio-economic nature. However, on the upside as indicated by a research in Greater Glasgow and Clyde Areas with longest life expectancy (which are usually those with the highest proportion of elderly) tend to have the shortest period of living unhealthy socio-economic factors.

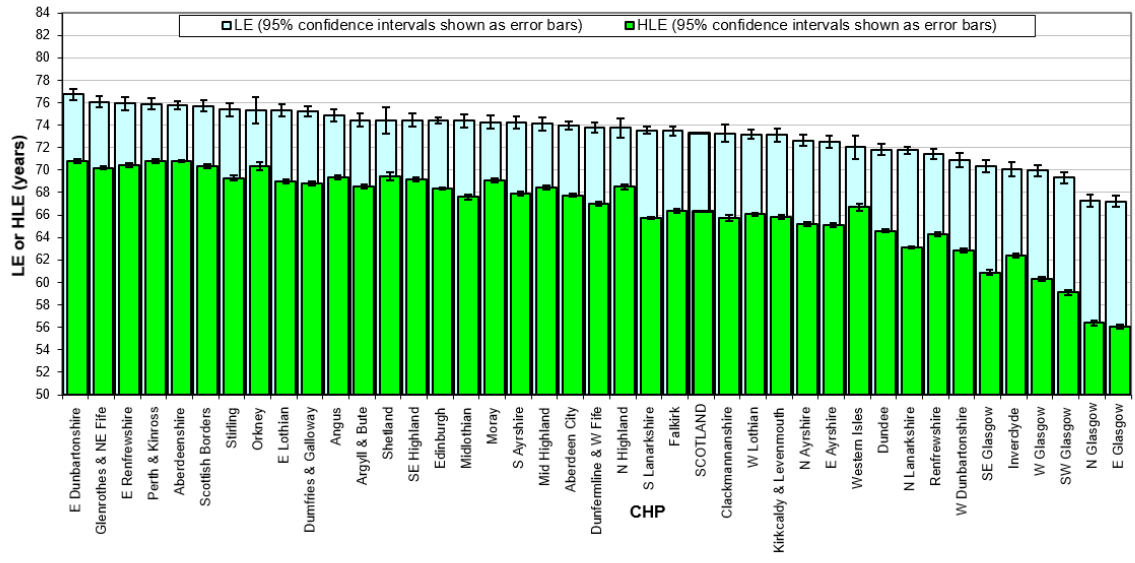
	Life Expectancy	Healthy Life Expectancy	Expected period 'not healthy'
East Dunbartonshire	76.7	70.8	5.9
East Renfrewshire	75.9	70.5	5.5
Renfrewshire	71.5	64.3	7.2
West Dunbartonshire	70.9	62.8	8.1
South East Glasgow	70.3	60.9	9.4
Inverclyde	70.1	62.4	7.7
West Glasgow	70.0	60.3	9.7
South West Glasgow	69.3	59.1	10.2
North Glasgow	67.3	56.4	10.9
East Glasgow	67.2	56.0	11.2

Figure 0-9- life expectation and healthy and unhealthy expectation in each part of Glasgow - (Source: ScotPHO,2013)

In the **Error! Reference source not found.**,**Error! Reference source not found.** show the LE and HLE for males and females in detachment of Scotland. The differences between LE and HLE shows the unhealthy life expectation.

Social Media in Health and Care Co-production

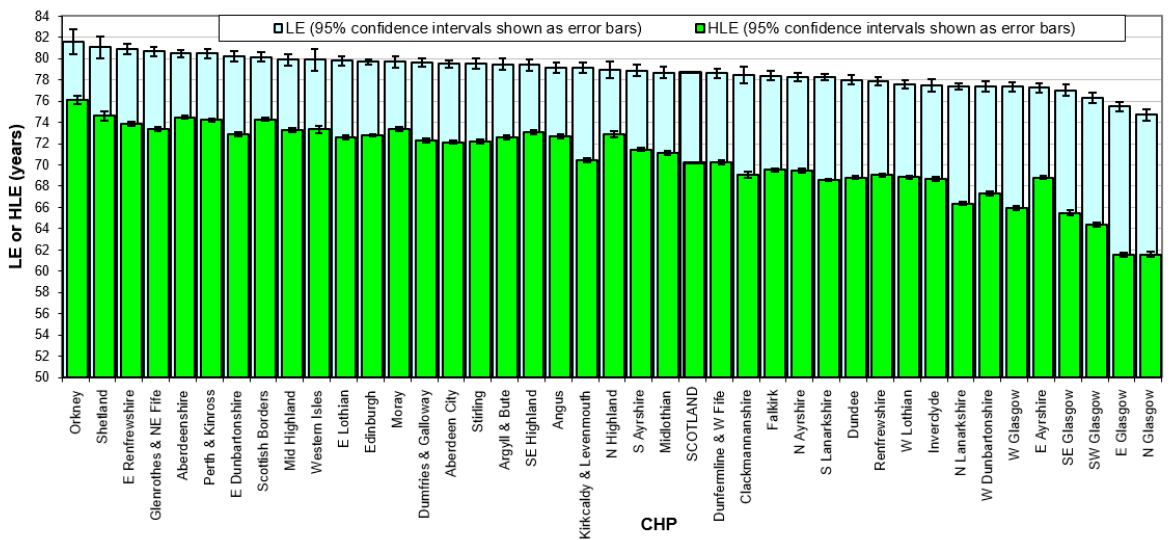
MALES, 5-year period 1999-2003



Source: abridged life tables (see technical report), using GROS mid-year population estimates and death registrations (by year of registration) and 2001 Census self-assessed health (reported as good/fairly good).

Figure 0-10- Male life expectancy and healthy life expectancy in Scotland

Life expectancy (LE) and healthy life expectancy (HLE) at birth, by CHP area in Scotland, FEMALES, 5-year period 1999-2003



Source: abridged life tables (see technical report), using GROS mid-year population estimates and death registrations (by year of registration) and 2001 Census self-assessed health (reported as good/fairly good).

Figure 0-11- Females life expectancy and healthy life expectancy in Scotland

A recent annual estimate of LE in Scotland shows that for boys and girls born in 2012 in Scotland the LE is 76.9 years (with 59.4 HLE) and 80.9 years (with 62.0 HLE) respectively. These figures show an overall improvement of health in Scotland over

the past few years. The figures show that the gap between LE and HLE is gradually decreasing.

The figure also shows a relationship between the gap between LE and HLE and different geographical and socio-economic groupings. For instance, in 2009 and 2010 LE and LHE of boys ranged from 70.1 and 50.0 (almost 20 years gap) in deprived areas to 81.0 and 68.5 (11.5 years gap) in least deprived areas. For girls, these numbers were 76.8 (LE) and 52.5 (HLE) (24.3 years gap) in deprived areas and 84.2 (LE) 70.5 (HLE) (14.3 years gap).

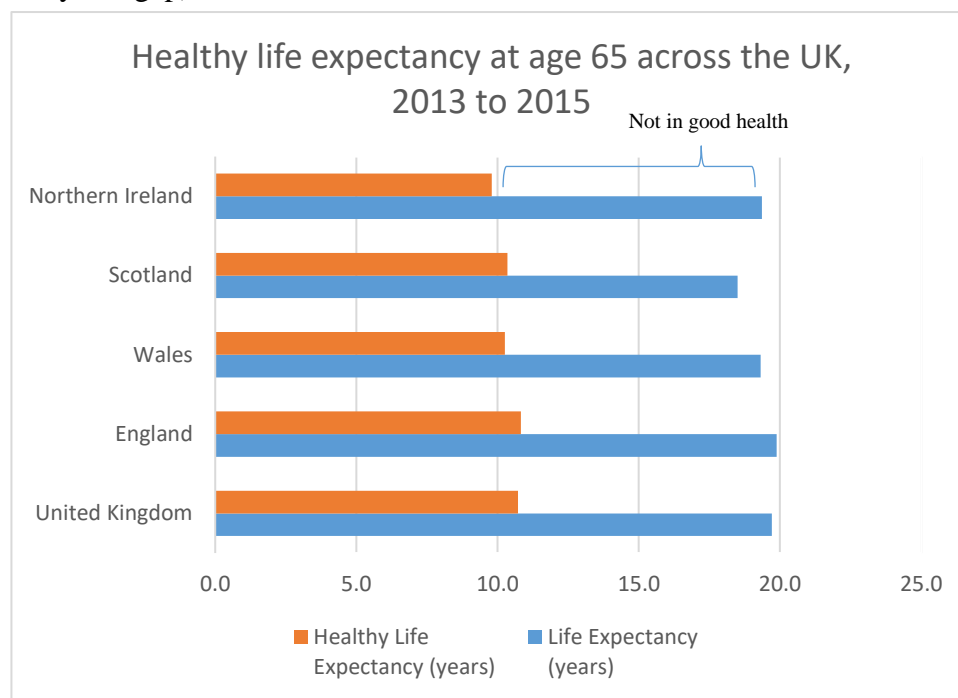


Figure 0-12- Life expectancy and healthy life expectancy in the UK – (Source: Office for National Statistics)

Overall both LE and HLE are considerably lower in Scotland compared to that of the UK (**Error! Reference source not found.**). Than in the UK as a whole, for both males and females. In fact, Northern Ireland and Scotland’s LE are lowest in Western Europe but although male’s HLE is low compared to many EU countries, female’s HLE is higher.

Appendix 2 - Template of forms

Template of information sheet

Social Media with health and care co-production

Information Sheet

Hadi Daneshvar (h.daneshvar@ed.ac.uk)
University of Edinburgh – School of Informatics

You are being invited to take part in an interview as part of the above study. Please take time to read this information sheet which describes the goals of the study and what we are asking you to do. Thank you for taking the time to read this leaflet. We appreciate you are busy and would like to thank you in advance for taking the time to consider this request.

Project Overview

World population is getting old. EU health systems face the triple challenge of ageing, fiscal restriction and inclusion. Consequently we are observing a huge increase in demand for care accompanied by significant budget reductions. Governments are searching for ways to meet health and care needs at lower cost while maintaining quality of care. So they are intending to reform systems to improve coordination and integration. The priorities identified by the Scottish government emphasise the need for integrating health and care which clearly leads to the use of co-production concept (delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours). The full participation of informal carers (6.5 million people) in the co-production of health and care has the potential to play a significant role in the sustainability of health and care delivery. A pressing issue is how to coordinate this massive resource with the formal health and care system to enable true co-production of health and care.

In this study we aim to investigate the current and possible future uses of social media (SM) as an enabler of co-production (in particular co-delivery and co-design), in health and care to improve coordination of health and care system. By SM we refer to internet based applications shaped around the concept of web 2.0 on which users can generate content and create and exchange them. The table shows our four areas of concern around use of SM for health and care. In this regard, to achieve the goals of this research, we investigate that the opportunities and risk of the applications that work in each area for leading make possible co-delivery and co-design for improving coordination:

		Health and Care	
		Current Service	Change of Services
Social Media	Current App.	Use of current SM in existing situation	Current SM help to change health and care services
	Redesign	New SM to cater for the current health and care services	New SM for new health and care Services

In doing so, we wish to explore the experiences, attitudes and organisational consequences of implementation from the perspectives of key stakeholders. So we are inviting you to the interview in order to gain insights into your views/opinions and experiences.

Taking part in the interview

If you decide to take part please sign the consent form. You are still free to withdraw at any time.

We may invite you to take part in a maximum of 3 interviews, however if you wish to be interviewed once only, we will be very happy to arrange this. Most interviews will be one-to-one interviews which will take no longer than 45 minutes each. Interviews may be conducted face-to-face or Skype or on phone.

We will then arrange the interview at a time of your convenience.

Confidentiality

All interview transcripts will be anonymised, and anything you say during an interview will be confidential.

Study results

The results of this study will be published in relevant journals and presented at conferences. No individual participant will be identifiable in any of the published material.

Who do I contact for further information?

For further information about this study please contact the researcher: Hadi Daneshvar at h.daneshvar@ed.ac.uk

Template of Consent Form

Social Media with Health and Care Co-production

INTERVIEW CONSENT FORM

Please tick all the boxes to give your consent to participate in this research. If you don't feel able to all the boxes, or if you change your mind at any point, we will not include you in the research.

	Tick
I have read the information sheet and asked any questions I want, which were answered to my satisfaction.	
I have been informed of the objectives of the study, my role within it, and the tasks I am expected to undertake.	
I understand that I am free to withdraw from the study at any time and without giving a reason for withdrawing.	
I have been reassured that the procedures adopted by the researcher to ensure my anonymity as a participant will be maintained.	
I am happy to be quoted (for example, when the research is published) so long as my name isn't mentioned.	
I agree to participate in the study.	

Name of participant (capitals):

Signed: Date:

I agree to be contacted again for a follow-up interview (please tick)

Appendix 3 - Social Media and Self-Management Report

Social Media and Self Management Report



Health and Social Care Alliance Scotland (the ALLIANCE)
Venlaw Building, 349 Bath Street
Glasgow, G2 4AA

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