







STUDY PROTOCOL

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

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## Abstract

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

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

## Open Peer Review

**Approval Status** Awaiting Peer Review

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underpinning missed appointments and the interventions designed to address them.

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

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### Keywords

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

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## Plain English summary

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

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

## Introduction

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

Existing work around missed appointments has described the characteristics of patients who miss appointments, connecting demographic information to the likelihood of a patient missing

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

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

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

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

### A realist approach

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

### Aims, objectives and research questions

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

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

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

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

## Methods

### Patient and Public Involvement

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

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

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

We carried out an initial scoping search of MEDLINE and Web of Science (Science and Social Science Citation indexes) in January 2022 to inform the conceptualisation phase of the

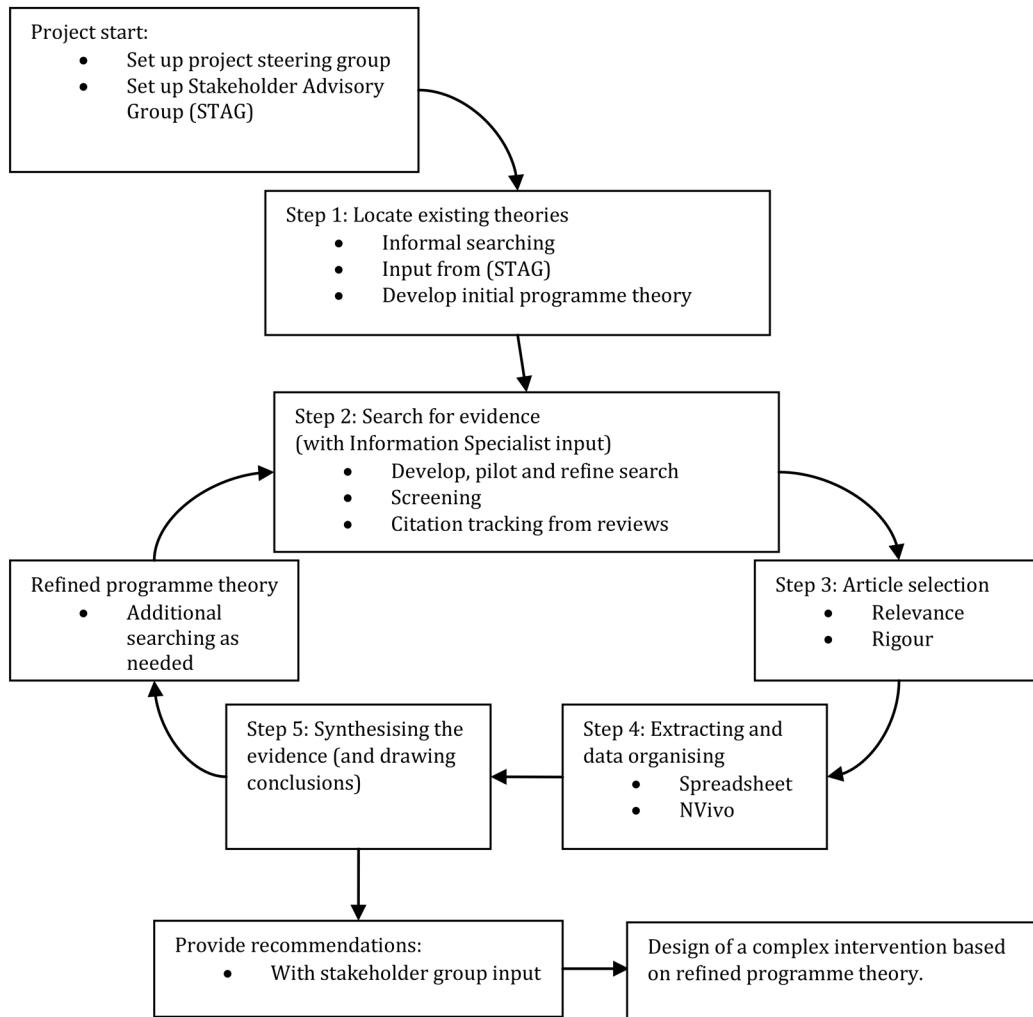


Figure 1. Realist Review process (adapted with permission from Wong *et al.*, 2015).

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

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

- **Navigation:** patients may have limited resources to overcome practical barriers including travel costs, phone credit, limited knowledge of how to navigate systems, or multiple and competing life priorities that are hard to prioritise.
- **Permeability and porosity:** GP services may be difficult to access – inflexible appointment times or systems, long waits for appointments, gatekeeping practices, no choice of clinicians or no access to additional support – that are poorly aligned with the resources or preferences of patients.
- **Presentation:** The act of presenting to general practice may be less of a priority in complex life circumstances. Poor physical or mental health may inhibit ability to attend, while patients may experience difficulties communicating or being heard in appointment spaces. Prior experiences of stigma or exclusionary practice



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

- **Adjudication:** where practitioners make judgements about patients' health, often these can stigmatise or feel exclusionary and limit future engagements. GP service dynamics may mean adjudications are made on heuristics, categorisations and moral schemas of staff, and there is limited space for trusted relationships to be formed or maintained.
- **Offers and resistance:** Problems in adjudication can mean the offers made to patients do not meet their hopes or expectations and can inhibit future engagement with services. Often, services view such non-engagement as patient negligence or choice rather than a form of resistance or negotiation that could be addressed by providing care through a "missingness" lens.
- **Local operating conditions:** the resourcing and context of service provision may prevent identification of patients at risk of "missingness", may create narrow routes for access and inhibit presentation and adjudication. Professional practice may not meaningfully account for those who are "missing" and respond with support or improved practice (see Dixon-Woods *et al.*, 2006).

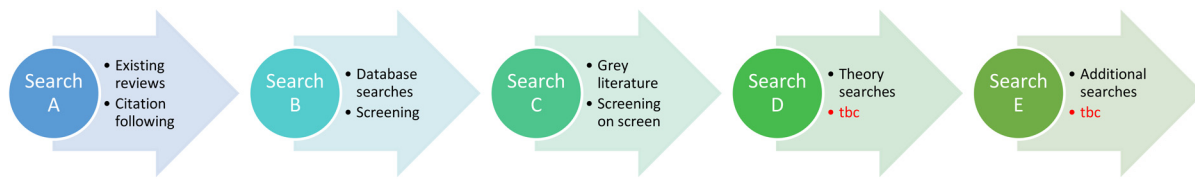
The framework will likely be complemented by other substantive theories in health inequalities, including structural vulnerability (Quesada *et al.*, 2011), fundamental cause theory (Phelan & Link, 2013) and other theories that speak to the causal dynamics underpinning the candidacy process.

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

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

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

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



**Figure 2. Stages of searching.**

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

- Studies in the NHS not relevant to appointments in primary care (typically outpatient or specialist settings, or screening programs).
- Studies on primary care in other locations, with studies labelled to allow future searching of locations – particularly those akin to the NHS, where healthcare is free at the point of use.
- Studies on missed appointments in non-healthcare settings in the UK.
- Studies of missed appointments not relevant to primary care and based in countries other than the UK.

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

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

### Data extraction and analysis

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

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

- Relevance: do sections of data within the document have relevance for development or refinement of the programme theory?
- Rigour and trustworthiness: are the data sufficiently trustworthy and plausible, and are they beneficial at the level of the programme theory.
- Analytical interpretations about CMOCs, including what the data says about what is functioning as contexts, mechanisms and outcomes and how these relate to each other to form emerging CMOCs.
- Assessments of what these data say about the relationships of the CMOCs and programme theory and how it might be altered or refined.

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

### Discussion and future directions

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

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

- 1. Define the problem and its causes.
- 2. Explore which causal or contextual factors are malleable and have the most potential for change.
- 3. Identify how to bring about change (i.e. the change mechanism(s)).

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

## Data availability

### Underlying data

No underlying data are associated with this article.

## Extended data

Open Science Framework: Developing interventions to reduce ‘missingness’ in health care

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

The project contains the following extended data:

- Medline search strategy.xls
- Missingness – PRISMA 19.4.23.pdf
- PRISMA-P-checklist 19.4.23.pdf

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

## Software availability statement

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

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

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

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

**Nvivo** is proprietary software but alternatives include Taguette.

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