

# Value, challenges and practical considerations when designing, conducting and analysing a longitudinal qualitative study in family medicine

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**To cite:** Wanat M, Boylan A-M, Borek AJ. Value, challenges and practical considerations when designing, conducting and analysing a longitudinal qualitative study in family medicine. *Fam Med Com Health* 2021;9:e001283. doi:10.1136/fmch-2021-001283

## ABSTRACT

Qualitative longitudinal design has a long tradition in a variety of social science disciplines and is increasingly used in applied healthcare research, including family medicine. While there are many definitions of longitudinal qualitative research (LQR), its most common characteristics are multiple data collection points and its focus on temporality, which prioritise the study of change and continuity. Thus, LQR can provide insights into the nature, causes and consequences of change (or its absence). In this paper, we discuss the key steps and considerations related to designing and conducting LQR in family medicine and community health. These include (1) deciding on the length of data collection and timing and number of interviews, (2) planning recruitment: attrition versus oversampling, (3) approaching data collection: asking the same or different questions, (4) planning and conducting the analysis and writing up findings, and (5) conducting ethical LQR. We also highlight what LQR can offer family medicine and community health, including (1) allowing exploration of views and experiences of a variety of participants over time; (2) following participants through important transitions; (3) studying implementation of new practices, processes or interventions; (4) exploring the importance of historical change and/or macro context on individuals' lives; and (5) developing a deeper understanding of phenomena under study. While a lot of attention has been paid to using LQR when studying patients' and/or carers' experiences, we highlight its value when studying a variety of actors relevant to family medicine, including healthcare professionals and policy makers.

also increasingly used in applied healthcare research,<sup>4</sup> including family medicine.

There are many definitions of LQR in the literature, partially depending on the field in which they are used. Some definitions specify the frequency of data collection<sup>5</sup>; others focus on duration of data collection,<sup>6</sup> while some promote a more flexible approach, noting that each study is different and may also need a different approach.<sup>7</sup> However, what they all highlight is that the key characteristic of LQR is both multiple data collection points and a focus on temporality, allowing the study of not only change but also continuity to become a priority.<sup>8,9</sup> Focusing on change and continuity can provide insights into the nature, causes and consequences of change.<sup>1</sup> Like quantitative research, LQR can also give us indications of increases, decreases, constancy and idiosyncrasy.<sup>10</sup>

There are different ways in which one can conduct LQR. First, LQR can be used as either a stand-alone study or alongside other methods.<sup>1,3</sup> Second, longitudinal design may be planned from the outset of the study when researchers plan in advance to conduct a number of interviews over time, or it may be added in after the first data collection point if the topic or the data seem likely to benefit from subsequent data collection.<sup>11</sup> Finally, unlike in a narrative study where one invites participants to describe their life events in a single interview, one can conduct LQR using a prospective longitudinal design, which involves following the same individuals over a period of time or employing a recurrent cross-sectional design, which involves recruiting different participants at different time points.<sup>1</sup>

## INTRODUCTION: WHAT IS LONGITUDINAL QUALITATIVE RESEARCH (LQR)?

The value of qualitative research in applied healthcare research, including primary care, is now widely recognised and well described.<sup>12</sup> In recent decades, as the qualitative research field has matured, we have also seen exciting innovations, including the use of more complex designs, such as longitudinal qualitative design. While LQR has a long tradition in a variety of social science disciplines,<sup>3</sup> it is

## LQR AND PRIMARY CARE

LQR has been developed and extensively used in social sciences, including anthropology,



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education and psychology, but it is also a useful, yet so far underused, approach in primary care and family medicine research. While some of the overarching principles and steps of designing the LQR are similar across disciplines, what they mean for each discipline or setting may differ. LQR's focus on change and continuity lends itself very well to the healthcare context and primary care for numerous reasons. First, as patients often experience both health and primary care services over time, prospective LQR can enable us to follow these experiences,<sup>12</sup> shed more light on why they may change or not,<sup>4</sup> and help identify patients' changing needs.<sup>13</sup> Second, LQR may be useful when following both individuals (including primary care patients and healthcare professionals (HCPs) and relevant primary care organisations through important transitions to explore how they adjust, make sense of and deal with these transitions.<sup>3,4</sup> Third, LQR can also be used to study the process of implementing new practices in primary care in the context of both clinical trials and routine clinical care,<sup>5</sup> thus highlighting barriers and facilitators to embedding new processes, practices or interventions at different stages. Finally, the individual experiences of change and continuity in family medicine can occur within the broader, historical context, which can also shape these experiences. LQR can help us to understand these relationships.<sup>1</sup>

### STEPS FOR DESIGNING, CONDUCTING AND ANALYSING LQR

In this paper, we aimed to (1) introduce LQR to family medicine researchers and clinicians; (2) highlight important steps, considerations, challenges and opportunities related to LQR; and (3) signpost to other literature that may be helpful for those new to LQR. We discuss key steps related to conducting LQR with particular emphasis on applications in family medicine and primary healthcare research. The steps presented are structured around key stages of any qualitative study, including planning and design, recruitment and data collection, and data analysis. We also discuss ethical considerations as cross-cutting these stages. As experienced qualitative researchers in primary care, we draw on wider applied healthcare research when discussing these steps as well as our experience of conducting qualitative research (including longitudinal design) while highlighting papers that have used longitudinal qualitative design in primary care in order to showcase the different approaches and the value of LQR in this particular setting. **Table 1** provides more information on selected examples of longitudinal qualitative studies in family medicine and community health research. This is not an exhaustive list; rather, these were chosen by the authors to illustrate the diversity of LQR in primary care, including methodological approaches, aims and samples.

It is important to highlight that the steps and considerations presented in this paper are applicable to 'experiential' methodological approaches<sup>14</sup> (such as interpretative phenomenological analysis (IPA), narrative analysis or

thematic analysis) which focus on understanding people's views and experiences rather than discursive approaches (such as discourse analysis and conversation analysis) which are concerned with how language is used to construct a particular version of a reality. In relation to methods of data collection, we focus here on steps relevant to interviews and focus groups as these are one of the most common methods in LQR<sup>15</sup> and in primary care research as they allow exploration of people's views and experiences.

### Step 1: deciding on the length of data collection and timing and number of interviews

When employing LQR, researchers need to decide on three key inter-related aspects: (1) the length of the time needed for data collection, (2) timing and spacing of the interviews, and (3) number of interviews. Neale<sup>1</sup> suggested thinking of the overall length of data collection as the *time frame* of a qualitative longitudinal study, and of the number, timing and spacing of the interviews as the study *tempo*. Together, time frame and tempo can be seen as a framework for designing and conducting LQR.

#### Length of data collection

One of the key considerations when designing LQR is to decide on the overall length of the data collection period. The time frames of published longitudinal studies in primary care vary, as they are (rightly) guided by the study focus and research question. For example, a recent study on experiences of primary care HCPs on implementing remote consultations during the COVID-19 pandemic focused on the first wave of the pandemic and thus collected data over a period of 4 months (April–July 2020)<sup>20</sup> (see also **table 1**). However, some topics may not lend themselves to such clear cut-off points. For example, when studying patients' recovery from a particular treatment or adjustment to a new diagnosis, for example, asthma, it may be difficult for researchers to decide for how long they should follow the participants. Being guided by clinical information (eg, the 'usual' recovery time) might be useful for researchers while being mindful that individual trajectories may differ. Also, stopping data collection sooner may not capture some of the aspects of recovery. Finally, researchers may want to consider other factors such as availability of resources and staff.

#### Timing and spacing of interviews

The timing of the interviews is also crucial, and researchers may want to consider three approaches.

#### Approach 1: data collection around researcher-led events

One approach to deciding the timing of the interviews may involve researchers trying to define 'events' which may act as important time points for data collection. These time points need to be decided in relation to the population and topic under study. When exploring patient experiences of the illness trajectory, the timing of the interviews may be based on the events linked to their journey, which, for example, may involve talking

**Table 1**

Contribution	Paper	Study aims	Context/ setting	Participant group	Participants (n)	Data collection points (n) and interviews (total n)	Data analysis and presentation
1. Exploring views and experiences of variety of participants over time.	Murray <i>et al</i> <sup>52</sup>	To compare the illness trajectories, needs and service use of patients with cancer and those with advanced non-malignant disease	Community	Patients with newly diagnosed inoperable lung cancer; patients with advanced cardiac failure, informal carers and their HCPs	40 patients, numbers not reported for carers and HCPs	93 with patients (53 with carers and 73 with HCPs) Interviews conducted at 3 monthly intervals for up to a year Additional interviews with carers after bereavement	Narrative analysis, 'themes spanning time' approach
	Checkland <i>et al</i> <sup>47</sup>	1. To examine how CCGs approached the task and process of setting themselves up. 2. To examine how CCGs are structured and what roles GPs adopt.	Primary care	Managers, HCPs and lay members	91 participants in phase I, 42 participants in phase II	Multimethod approach including 96 interviews in phase I (18-month period) and 42 interviews in phase II (2-year period)	Thematic analysis within wider realist approach framework, themes spanning time approach
2. Following participants through important transitions.	Lawton <i>et al</i> <sup>29</sup>	To explore patients' perceptions and experiences over time of the devolvement of diabetes care from secondary to primary care healthcare setting	Secondary and primary care	Patients with diabetes	20 patients	80 interviews with patients at four time points over 4 years	Thematic analysis, themes spanning time approach
	Gordon <i>et al</i> <sup>20</sup>	To explore trainee doctors' experiences of the transition to trained doctor	Various medical settings	Trainee doctors expected to complete training within the next 6 months	20 participants	38 interviews at two time points (before completing training) and within 12 months of completing training, also audio diaries	Framework analysis, themes spanning time approach

Continued

Table 1 Continued

Contribution	Paper	Study aims	Context/ setting	Participant group	Participants (n)	Data collection points (n) and interviews (total n)	Data analysis and presentation
3. Studying implementation of new practices, processes or interventions.	Linmans <i>et al</i> <sup>30</sup>	To explore the processes involved in the provision of a lifestyle intervention to patients with type 2 diabetes mellitus by HCPs in primary care	Primary care	Patients with diabetes taking part in a lifestyle intervention in primary care, HCPs delivering the intervention	Not reported	Interviews with patients after each consultation with HCPs, interviews with HCPs before and after delivering the intervention	Framework analysis with phenomenological approach, themes spanning time approach
	Laing <i>et al</i> <sup>49</sup>	To explore the contextual factors that influenced the nature and extent of implementation and sustained use of the PINCER (intervention in diverse settings over time	Primary care	Staff members from general practices, and policy makers	48 participants	48 interviews with staff depending on the short-term, medium-term and long-term involvement in the intervention; further interviews planned	Thematic analysis, themes spanning time approach
4. Exploring the importance of historical change and/or macro context on individuals' lives.	Murphy <i>et al</i> <sup>60</sup>	To examine how clinicians and managers dealt with the rapid implementation of remote consulting	Primary care	GPs, practice managers and nurses	41 participants	84 interviews conducted across four time points over 4 months	Framework analysis, combined themes spanning time and 'themes tied to time points' approaches
	Guzman <i>et al</i> <sup>51</sup> (protocol)	To explore the experiences of community-dwelling older adults during COVID-19	Community	Adults over 65 years old living in community settings	Anticipated sample of 30 participants	Data to be collected at two time points 3–10 weeks apart	Thematic analysis, plans for themes tied to time points approach
5. Developing a deeper understanding of phenomena under study.	Smith <sup>18</sup>	To explore women's transition into motherhood	Community	Women within the first trimester of their pregnancy	four participants	16 interviews at 3, 6, 9 months of pregnancy, and 5 months after the birth of the child	IPA, themes tied to time points approach
	Nissim <i>et al</i> <sup>22</sup>	To contribute to the understanding of the desire for hastened death in the context of advanced cancer	Community	Patients with advanced lung or gastrointestinal cancer	27 patients	54 interviews every 2–4 months	Grounded theory approach, themes spanning time approach

CCG, clinical commissioning group; GP, general practitioner; HCP, healthcare professional.

to patients shortly after being diagnosed or after they complete their treatment.<sup>16 17</sup> One may also conduct interviews before and after the event, with the aim of understanding and comparing one's expectations and experiences.<sup>18 19</sup> For example, Gordon *et al* studied the process of transition from trainee to trained doctor and conducted interviews with participants before they graduated from their degree (thus studying their expectations of what it means to become a doctor) and after they obtained their degree.<sup>20</sup> Similarly, Lester *et al* interviewed patients within 6 months of inception into the early intervention service and after being discharged to primary care.<sup>19</sup> Neale<sup>1</sup> suggested that having such clear events can be very helpful for establishing a clear baseline as well as a closure point for a qualitative longitudinal study and urged researchers to think carefully how the beginning and the end of the study will be defined.

### **Approach 2: data collection around participant-led events**

Defining such events may not always be beneficial, and some highlighted the benefits of flexibility in deciding the timing of data collection<sup>1 7</sup> and allowing for conducting interviews around, for example, unexpected events. This may mean that researchers would be guided by the participants, who would advise when they experience any significant events in relation to the phenomena of interest. This approach is known as the mirroring process,<sup>1</sup> where data collection mirrors the events in participants' lives. Consequently, researchers may be collecting data around events defined in the same way but which may not occur at the same intervals for all participants.<sup>21</sup> However, others also highlighted the drawbacks of this approach, noting that in larger samples, it may be difficult to keep track of all the participants and conduct interviews around the key events.<sup>4</sup>

### **Approach 3: data collection based on pre-established, regular intervals**

Deciding on the events may not always be possible. For example, Murray *et al*<sup>13</sup> highlighted that defining key events in relation to patient experience requires a researcher to have an understanding of a 'typical' illness trajectory of a given condition. For certain conditions, these may be less well defined. In such situations, it may be useful to conduct interviews at regular intervals over a period of time to facilitate an in-depth understanding of issues during a particular period rather than around key events. Nissim *et al*, who studied the experiences of patients with advanced cancer with the focus on the desire for hastened death, largely adopted this approach by interviewing their participants at 2–4 month intervals.<sup>22</sup> However, they also shortened these intervals in a number of scenarios including when participants started new treatments; self-reported measures indicated a change in their physical or psychosocial distress or patients' condition began deteriorating. The study thus highlights the benefits of a flexible approach, combining data collection at regular intervals with participant-led events.

### **Number of interviews**

The third aspect, the number of the interviews, will be partially framed by the two aspects discussed previously: the length of data collection and timing of the interviews. For example, if a researcher decides to collect data over a 1-year period, the significant events participants experience in their lives will somewhat indicate the number of interviews as well. However, it still leaves researchers scope to decide on the number of interviews. Neale *et al*<sup>23</sup> suggested that one way of viewing LQR may be to see it on a spectrum from intensive to extensive. The most intensive approach may mean that the numerous data collection points can lead to almost blurred boundaries between time points, which have been referred to as a 'description through time'.<sup>1 23</sup>

Regardless of the approach, it is crucial to plan the length of data collection, timing and frequency of the interviews to facilitate the primary aim of the LQR, which is to study change and continuity.<sup>11</sup> Also, these three aspects will need to be guided not only by the research question but also by resources and (existing) expertise within the team. Having multidisciplinary teams can be beneficial as advice from both clinicians and patients<sup>24</sup> on, for example, a typical clinical pathway or illness trajectory can be crucial in deciding on the timing and number of interviews and, ultimately, the success of the study.

### **Step 2: planning recruitment: attrition versus oversampling**

Recruitment and sampling are important aspects of all qualitative research but can be particularly challenging in LQR. One of the key aspects is to decide on sample size, which may have numerous implications.

First, researchers need to strike a fine balance between sampling a sufficient number of participants and oversampling. While it is often recommended that researchers allow for sample attrition by recruiting more participants for the initial interviews than needed, in the studies where retention is high, this may lead to an excessively large sample and dataset. In this case, researchers may have to decide whether they want to follow up all the participants or a subset, taking the implications of that into account. For example, Calman *et al* described how initial oversampling of their participants (caregivers of cancer patients) led to a decision not to interview some participants at subsequent time points, which created tensions between researchers and participants.<sup>4</sup> Equally, high levels of attrition may lead to bias in the sample and the subsequent study results.<sup>25</sup> For example, Lester *et al* highlighted that they faced problems in accessing contact details of participants for the follow-up interview 3 years later and thus had relatively high attrition rate (33% of participants took part in the follow-up interview).<sup>19</sup>

Second, as in all qualitative research, sample size will influence the depth of the analysis. Smaller samples may allow a more in-depth understanding of individual experiences and lend themselves well to methodologies that value an idiographic approach (eg, phenomenology). For example, Smith conducted interviews with four women as

case studies to develop an initial theory of transitions to motherhood. In contrast, larger sample sizes may allow, through their breadth, the identification of patterns and the influence of external factors shaping individuals' experiences to be recognised.<sup>1</sup> Neale<sup>1</sup> also pointed out that a small number of participants do not necessarily mean a small dataset, given the number of times participants might be interviewed.

### Step 3: approaching data collection: asking the same or different questions

One of the key considerations when conducting subsequent interviews in LQR is deciding on what questions will be asked at each time point. Holland *et al*<sup>3</sup> suggested two approaches: one involves researchers asking the same set of questions at each time point, thus facilitating close mapping of the data at all time points. The second involves anchoring data collection on specific topics of interest which in turn may mean asking the same and/or different questions related to these topics. The reason for this is that some questions will only be relevant at particular time points. This will be especially relevant for researchers conducting interviews around key events, as described earlier. For example, in interviews with patients with limiting illness over 18 months, Worth *et al* covered the majority of the same topics at all time points (eg, patients' needs) while also asking some questions only at particular time points (eg, about illness history at interview one only).<sup>26</sup> In contrast, Lester *et al* used two different topic guides and asked different questions at each time point.<sup>19</sup> Researchers need to consider whether and how participants may be encouraged to discuss change in their lives. Here, we outline three approaches for doing this. One approach may involve providing a participant with a summary of a previous interview at the beginning of each interview.<sup>27</sup> This may be useful in providing a starting point for the subsequent interview and can be an example of member checking, an approach used to enhance trustworthiness of qualitative data.<sup>28</sup> However, care must be taken when preparing such a summary as researchers could inadvertently impose their interpretations of the previous interview, thus distorting the participant's story and affecting how they approach the subsequent interview. An approach facilitating a dialogue where a researcher summarises the previous interview(s) while inviting participants' views on it might be more constructive. Such an approach can provide an opportunity for participant reflection and enhance analysis (see step 4). A second approach may involve focusing the summary on more factual events, thus acting as a reminder of when the last interview took place. A third approach may be to encourage participants to reflect on any changes they have witnessed in their lives. Researchers may want to ask participants directly whether they have experienced any changes in their lives, as well as what remained the same, and more importantly, how they feel about it. For example, Lawton *et al* used this approach when studying the experiences of patients with diabetes

transitioning from specialist care to primary care. They encouraged participants to reflect on any changes related to their contact with diabetes services and HCPs since their last interview, as well as their understandings of why their service contact had changed over time.<sup>29</sup>

### Step 4: planning and conducting the analysis, and writing-up findings

When planning and conducting analysis in LQR, the researchers should consider (1) aims and questions that guide the analysis, (2) which approach to the analysis and writing up is appropriate for the research questions and objectives, and (3) practicalities involved in the analysis.

#### Aims and questions guiding LQR analysis

As the main aim of LQR is to identify change and continuity over time in phenomena of interest, the analysis needs to focus on exploring and identifying *how* and *why* change occurs or not over the study period. The analysis may also aim to identify different types of change. Researchers may want to explore the types of change proposed by Lewis<sup>5</sup>: individual, service, policy and structural; narrative (ie, 'unfolding of individual stories'); participant's reinterpretations (ie, 'rethinking or retelling of experiences described earlier'); and researcher's reinterpretations (eg, of what the participant described earlier). It is also important to identify when and why change is absent, and what remains stable and consistent and why.

Asking different types of questions of the data can help guide the analysis. Researchers need to relate to the research aims and questions, explore the different types of change and strive for a comprehensive understanding of the dataset, including how the analytical categories and codes relate to each other. For example, Saldaña<sup>7</sup> suggests using three types of questions to facilitate the analytical process: framing questions to capture the context and influences (eg, what contextual and intervening conditions appear to influence and affect participant changes through time?); descriptive questions to capture information to help answer questions (eg, what happens, increases or emerges through time?); and analytical and interpretive questions to integrate the descriptive and framing information (eg, which changes interrelate through time?).

#### Approaches to analysis

After deciding on research question/aims and the data collection methods, researchers need to select an appropriate analytical approach. They may want to consider two common approaches (or a combination of both) commonly described: (1) recurrent cross-sectional (ie, comparing multiple time points) and (2) trajectory or longitudinal (ie, identifying development or narratives over time).<sup>4 9 12</sup> Using a theoretical approach/framework may help decide on the approach to analysis and presentation of findings<sup>4</sup>; for example, Murphy *et al* used the normalisation process theory constructs to structure the coding framework in their longitudinal study of the

implementation of remote consultations in primary care during the COVID-19 pandemic.

*Recurrent cross-sectional analysis* focuses on changes and themes at different time points at the level of the whole sample.<sup>4,9,12</sup> In this approach, each round of data analysis explores a particular moment in time, but it should also aim to capture the temporal aspect and change between time points. Helpful approaches include thematic analysis (especially when the codes used capture aspects of change/stability) and framework-based analysis (eg, charting themes per time points). The strength of the recurrent cross-sectional approach is in that it enables a comparison and identification of patterns across the whole sample and that it often remains grounded in the data. The drawback may be difficulty in capturing individual narratives over time,<sup>9</sup> which in turn may result in a description of each time point rather than an understanding of change.<sup>4</sup>

*Trajectory or longitudinal analysis* focuses on change of individuals or groups to identify trajectories of change over time.<sup>12</sup> It needs to include the same participants at different time points and can be facilitated by developing ‘case’ summaries or narratives that capture the changes and key themes across time for each participant. IPA might be particularly suitable to this approach, and a framework analysis may also be useful to identify the types of trajectories for subgroups of participants. The trajectory approach enables capturing and presenting the temporality of data, but it can be more difficult to capture and present patterns across the sample. With complex LQR datasets, combining cross-sectional and trajectory approaches and multiple types of analysis may be needed to capture the various aspects of the data.<sup>9</sup>

### Writing up the findings

As writing up the findings can form a part of, or refine, the analysis in qualitative research, it may be helpful to consider the analytical approach together with an approach to presenting the findings. Farr and Nizza<sup>15</sup> identified two common approaches to presenting the findings in longitudinal IPA papers, which may be relevant to other methodologies as well.

In the ‘themes tied to time points’ approach, each theme captures a time point or stage and includes a description of all aspects of the participants’ experiences relevant to that time point. In other words, each theme illustrates the different experiences apparent at each time point that contribute to the overall process of change/transition over time (eg, pre-event and postevent). Therefore, different themes could be identified at different time points. This approach may help present findings from the *recurrent cross-sectional analysis*. For example, Smith described women’s transitions to motherhood at different time points during pregnancy and after giving birth, with themes such as ‘Early pregnancy: adjustment and uncertainty’.<sup>18</sup>

In the ‘themes spanning time’ approach, the findings are presented in one set of themes with each theme

describing change over time. It may be that the focus is on a subset of themes to allow for including a more nuanced and in-depth account of change and commonalities and differences between participants. This approach may help present findings from the *trajectory/longitudinal analysis* and include descriptions of ‘cases’ or groups/types of trajectories. Most studies in primary care presented in [table 1](#) used this approach; for example, Lawton *et al* captured the changes over time in patients’ perceptions and experiences of transitions from secondary to primary diabetes care within themes, such as ‘Practice-based care: a mixed blessing’.<sup>29</sup>

A combined approach is also possible, such as with one theme that is divided into time points and other themes which span time. For example, Murphy *et al*<sup>30</sup> first summarised the changes over time during the transition to remote consulting and then used theoretical concepts to describe different types of changes. In all approaches it can help to present a single case and then highlight similarities and differences with other participants, label the quotes to indicate the participant and time point, and use paired quotes from the same participant that show change/progression (eg, before and after)<sup>15</sup> (eg, see Lester *et al*<sup>19</sup>).

### Practical considerations

With LQR analysis, researchers need to carefully think through and plan how to best manage the practical aspects of the analysis. First, this involves data management—LQR often generates large amounts of data over a prolonged period, so thoughtful, consistent and secure data management is critical. Researchers should plan consistent record-keeping (eg, labelling the interviews, researchers involved, recording summaries and reflections) and data anonymisation processes (eg, when and how it should occur) to allow engagement with participants over longer time while protecting their identities. It may help to record other relevant details to inform the analysis and interpretation, especially at later stages and in longer studies. These may include contextual details, such as records of events, changing policies, media stories, etc, which are relevant to the research topic. Agreeing a consistent approach to note-taking and researcher reflexivity can help capture, access and use the researchers’ reflections and reinterpretations over time.

Second, it is important to plan when the analysis takes place (eg, after each interview, sets of interviews, time points, at the end), what tools and strategies are used to manage the process and the amount of data, and who is involved. For example, Lewis<sup>5</sup> describes using different types of analysis at different points: summarising each interview after the interview within a framework organised by key themes (cross-sectional analysis) and developing ‘whole case’ summaries (a narrative analysis) after a number of interviews. Similarly, Thompson and Holland<sup>9</sup> describe a provisional analysis after each interview focused on processual features (eg, structure and absences), substantive content and researcher’s

reflections; then after a few interviews writing a ‘summary narrative’ for each location, identifying local themes and ‘case profiles’, and tracing changes and continuities in the individual narratives over time. Summarising and conducting a provisional analysis after each interview can help inform future data collection and make incremental progress with the analysis. Analysing the whole dataset at a later or the end stage of the study may be overwhelming when faced with a large dataset but may also enable more global, holistic meaning-making through an immersive and intense analysis of the whole dataset (rather than small ‘chunks’ of the data). Working with bigger datasets or longer studies often requires a team-based approach with different researchers contributing to different parts of the study and analytical process, which highlights the need for planning and consistency of the aspects discussed previously.

Finally, researchers need to consider the implications of the sampling on analysis and data management. Overly heterogeneous samples add complexity as comparisons could be made not only between participants and time points but also between groups of participants. For example, Calman *et al*<sup>4</sup> describe the challenges of analysing data from patients with different types of cancer and trying to identify common trajectories. Analysing data from multiple types of health professionals or patients can make it more difficult to identify common trajectories than when focusing the data collection and analysis on a more homogeneous group from the outset. However, the differences between subgroups of participants may only become apparent during data collection and analysis. In this case, the use of frameworks can help with analysing and comparing data between groups of participants.

### CONDUCTING ETHICAL LQR IN PRIMARY CARE

LQR is subject to the same ethical concerns and considerations as qualitative research. However, given the immersive and prolonged nature of the approach, there may be more opportunities for ethical complications to arise. LQR has the potential to affect participants and researchers in particular ways that warrant special consideration. Care must be taken to avoid undue intrusion into people’s lives and to minimise the distortion of the experience being researched.<sup>37</sup> Some ethical issues may take on a particular salience when LQR is conducted by clinicians-as-researchers in primary care, so it is vital that they understand and plan for how to mitigate these issues.

#### Issues of confidentiality and consent

Collecting data at multiple time points generates more data, and the amount and depth of data generated means that participants may be more readily identifiable, particularly in research within organisations or with discrete populations such as primary care, where patients may be more identifiable to clinicians than in other settings. Participants must be made aware of this and informed about how researchers will protect their

privacy and confidentiality. As such, consent must be seen as an ongoing iterative process,<sup>34</sup> with researchers informing participants of changes to the study or new developments as the research progresses to ensure their consent is always informed. Study materials should be clear, easy to follow, and prepared or reviewed by stakeholders, including patient and public involvement (PPI) contributors to ensure that they are sufficiently informative and acceptable to potential participants. They should provide comprehensive information about how the large volume of data will be securely stored and used in the research. Each time data is collected; participants must be informed of their right to withdraw from the study without their healthcare or rights being affected. In some instances, they may also need to be informed that data that have already been published cannot be withdrawn.

#### Establishing, maintaining and ending research relationships

Rapport building is an important part of any relationship between researchers and participants. Deepening relationships based on trust and familiarity invariably enrich the data and offer opportunities for producing a more complete analysis.<sup>13</sup> In LQR, researchers need to take care to ensure that relationships with participants do not become exploitative<sup>3</sup> and that appropriate boundaries are maintained. Clinician–researchers may find that disclosing their clinical status facilitates rapport-building and interviewing their own patients, with whom they have already established a rapport, may increase research participation, particularly among ‘seldom heard’ groups.<sup>31</sup> However, as patients may feel obliged to take part in research conducted by their clinician, it is important that invitations are made through a third party rather than by the clinician themselves.

There is potential for ‘blurred lines’ between participants and researchers to occur due to increasing familiarity and the repeated interactions that characterise LQR. For instance, Calman *et al*<sup>4</sup> found that the participants in their LQR study turned to researchers for information or advice about their diagnoses. This may particularly apply in LQR in primary care with clinicians as researchers and highlights the need to have a plan in place to deal with such occurrences. We suggest that primary care researchers can develop and maintain appropriate boundaries with clear information, discussions and reminders of the researchers’ role, and clarity over what they can and cannot offer participants. It is the researcher’s responsibility to ensure that they maintain appropriate professional boundaries and that participants remain safe. They might do this by acknowledging their dual role as clinician and researcher upfront, then explaining that offering medical advice in a research context is inappropriate, so patients should seek advice from their own clinician for any medical issues they face. Conversely, Hoddinott, a general practitioner (GP), suggests clinicians can offer advice, but that they should tell participants to raise their questions at the end of the interview.<sup>31</sup>



A common ethical concern for qualitative research relationships is the disparity of power between researchers and participants, with power being presumed to sit with researchers and particularly clinicians-as-researchers. However, Christensen<sup>32</sup> argues that power does not reside with the people but is embedded in the research process and can be negotiated. By its nature, LQR offers multiple opportunities to negotiate power and to minimise its impact on the research participants and process. To that end, researchers should carefully document the impact of relationships on the research and participants.<sup>3</sup> This will provide opportunities to reflect on and address power imbalances, in addition to providing helpful context for understanding the data. Issues of power may not always be a concern—for example, in the case of a GP interviewing GPs. Literature on this suggests that being a GP and having insider knowledge facilitates the research process and enriches the data.<sup>33</sup> It has been suggested that this is because of a shared knowledge and shared common experience. However, we would caution against presuming that sharing an experience is synonymous with sharing the same perspective. Researchers must set aside their prior assumptions and ask participants to explain what they assume to be shared assumptions. This may also help to overcome subsequent potential biases that might arise in analysis.

Participant attrition in LQR can be associated with power disparities, lack of rapport between researchers and participants, participant characteristics (eg, cognitive decline) or participation fatigue (including because of repetitious questions). As discussed in step 2, attrition needs to be considered when designing the research, and attempts to mitigate its impact should be implemented.<sup>13</sup> Establishing good rapport between researchers and participants may decrease the likelihood of participant attrition.<sup>34</sup> Efforts to do this need also to be considered in the design stage and decisions over whether participants interact with the same or various researchers need to be made. This is particularly important as there is also more chance of researcher attrition, given the length of LQR projects,<sup>4</sup> so teams should consider how to manage relationships with participants in the event of a researcher leaving midway through a project.

Equally, thought needs to be given to ending research relationships in LQR in a way that is satisfying for the participants. This needs to be managed from the outset by giving participants clear information about how many interactions they can expect to have with the research team. It may be appropriate to offer participants an opportunity to debrief at the end of the study to discuss their experience of the research and provide a defined endpoint.<sup>4</sup> This opportunity to debrief may be particularly important if the research has been conducted by a clinician based in the patients' general practice, where there is potential for them to see each other outside of the research context. In this case, clinician-researchers should discuss the participants' feelings about seeing them in their general practice and whether

it is appropriate to make an appointment with them in future.

### Emotional implications for participants and researchers

Consideration about the emotional implications of taking part in LQR is particularly important as the nature of the study design means that participants may be invited to discuss stressful, distressing or sensitive topics repeatedly over a period of time. Ethics committees may be concerned about the impact of asking people to discuss sensitive issues,<sup>35</sup> when discussing their experiences with a researcher may actually be cathartic.<sup>36</sup> In fact, LQR may offer more opportunities for catharsis than those found in other types of qualitative design. Murray *et al*<sup>13</sup> found that participants wanted to talk about sensitive issues, like death and dying, that they sometimes found it easier to talk to a researcher, and that talking in research settings made it easier for them to discuss these issues with friends and family.

LQR also has emotional implications for researchers<sup>37</sup>—even reading transcripts can provoke an emotional reaction.<sup>38</sup> Prolonged interactions with participants and data, particularly on sensitive or distressing topics, may exacerbate emotional reactions. Equally, researchers working with participants who might die during the course of the study (eg, Nissim *et al*'s study on desire for hastened death<sup>22</sup>) need to have a plan in place to deal with potential feelings of grief and loss. With all these risk factors, researchers may be at increased risk of burnout or 'researcher saturation'<sup>39</sup> in LQR, given the sustained nature of their involvement in the research. Researcher saturation may manifest as headaches, anxiety and distress<sup>39</sup> and may be the result of inappropriate management of emotional tension. Those involved in longitudinal studies on sensitive or distressing topics, in which they are repeatedly exposed to traumatic stories, may be most at risk. It is worth remembering that distressing data can affect anyone who interacts with it, including researchers, but also transcriptionists. In designing LQR, researchers have a responsibility to mitigate risk for everyone involved in the study, from participants to junior research assistants to typists.

Parker and O'Reilly<sup>40</sup> propose a framework for managing ethical risk. It involves raising awareness among the research community about the impact of qualitative research on researchers. Although it is not specific to LQR, it certainly is applicable, particularly in primary care, where it may be assumed that the skills associated with qualitative interviewing are similar to clinical interviewing in consultations.<sup>31</sup> It calls for specialist training for researchers to help them appraise, identify and manage risk. It also highlights the importance of transparent risk assessment by institutions and calls for teams to adopt a collaborative approach, ensuring researchers have an established support network and access to confidential spaces for debriefing.

### Ethical conduct must be iterative and reflexive

Like all qualitative research, the emergent and iterative nature of LQR studies in primary care means that

ethical issues cannot be entirely predicted. Therefore, it is important that researchers approach ethical risk assessment in qualitative research as a reflexive and iterative process.<sup>41</sup> This applies equally to LQR. Teams must have explicit processes in place to increase the chances of ethical concerns being addressed before they have an adverse effect on participants. PPI can ensure that researchers are aware of the scope and range of possible ethical issues that may arise in their research.<sup>42</sup> Reflexivity, the consideration of the impact of the researcher on the researched,<sup>43</sup> is an important practice in all aspects of LQR. Self-awareness and reflection throughout can prevent ethical quandaries from arising and can minimise the researcher's impact on the research process.

### CONTRIBUTION TO FAMILY MEDICINE AND COMMUNITY HEALTH RESEARCH

Throughout the previous sections, we have described how LQR could be used to study change and continuity in healthcare, drawing on examples from primary and community care. In this section, we make a further case for how LQR can be a valuable approach in family medicine and community health research. We summarise five potential contributions of LQR and its relevance to these fields.

#### Exploring views and experiences of a variety of participants over time

Exploring views and experiences of participants over time is one of the most commonly used and suggested uses of LQR, which can be invaluable in family medicine. First, following patients' and/or carers' experiences of health and care in primary and community settings can aid in identifying what matters to them over time and in recognising their (changing) needs.<sup>13</sup> Previous studies have explored patients' and/or carers' changing experiences of different conditions, including diabetes,<sup>44</sup> chronic obstructive pulmonary disease<sup>45</sup> or heart failure.<sup>46</sup> Second, LQR can be used to study HCPs' views and experiences within their work context. It can be useful in identifying professionals' (changing) views, experiences of how they deliver care or the challenges they face. Third, LQR can be used to study experiences of other key actors in family medicine, such as policy makers responsible for designing or commissioning primary care services.<sup>47</sup>

#### Following participants through important transitions

LQR may also be useful when following participants through important transitions and exploring how they adjust, make sense of and manage them.<sup>3 4</sup> For patients, this may mean following them through transitions related to their health and healthcare use, and identifying key barriers and facilitators they face when transitioning through services (eg, see Lester *et al* and Lawton *et al* in [table 1](#)).<sup>19 29</sup> Transitions, such as changing jobs or progressing through career pathways, can also be a useful

lens when studying HCPs' experiences (eg, Gordon *et al*<sup>20</sup>).

#### Studying implementation of new practices, processes or interventions

LQR can also be used to study the process of implementing new practices, processes or interventions alongside clinical trials, as well as in routine clinical care,<sup>5</sup> thus highlighting barriers and facilitators to embedding new processes, practices or interventions at different stages. Qualitative methods are now a well-recognised way of studying implementation of interventions alongside evaluative studies (also known as process evaluation<sup>48</sup>) and in service evaluations; they can contribute to an understanding of what is implemented and how, how an intervention produces change, and how context can affect implementation and outcomes of an intervention.<sup>48</sup> However, the longitudinal design is still not widely used, including in family medicine. Studies which used it highlighted the benefits of doing so, including more dynamic understandings of key barriers and facilitators to implementation of new processes,<sup>30</sup> and whether and how these barriers and facilitators may be specific to different stages of the project.<sup>49</sup>

#### Exploring the importance of historical change and/or the macro context on individuals' lives

As highlighted by Holland,<sup>8</sup> LQR can also contribute to studying change at a historic level, and the relationship between micro, meso and macro dimensions can be very helpful when illuminating the relationship between individual experiences and social change.<sup>1</sup> The COVID-19 pandemic can be one example of such historical change, which may be of relevance for studying both patients' and HCPs' experiences (eg, studies by Murphy *et al*<sup>50</sup> or Guzman *et al*<sup>51</sup>). These studies can highlight how external events may affect both patients' and HCPs' experiences of receiving and delivering care, and how LQR is able to capture participants' evolving experiences in relation to historical change.

#### Developing a deeper understanding of phenomena under study

Collection of data over time can also contribute to building a theoretical model by gaining a more in-depth understanding of phenomena of interest. For example, Smith<sup>18</sup> highlighted the value of longitudinal interviews in gaining a detailed insight of women's experiences during and after pregnancy, which led to developing a theoretical model of women's transition to motherhood.<sup>18</sup> Equally, doing numerous interviews not only can illuminate the process of change but also, through building better rapport with participants, can facilitate collection of more detailed data.<sup>11</sup>

## CONCLUSIONS

LQR has much to offer family medicine and community health: allowing exploration of views and experiences of a variety of participants over time; following participants through important transitions; studying implementation of new practices, processes or interventions; exploring the importance of historical change and/or the macro context on individuals' lives; and developing a deeper understanding of phenomena under study. While a lot of attention has been paid to using LQR when studying patients' and/or carers' experiences, we highlight its value when studying a variety of actors relevant to family medicine, including HCPs and policy makers. By introducing the readers to some of the key considerations related to planning, conducting and analysing LQR in family medicine and community health, we hope it will help the primary care community to use this approach and lead to the conduct of high-quality research and, consequently, improved healthcare.

**Contributors** MW conceived the study and led the drafting the manuscript. A-MB conceived the study and drafted the manuscript. AJB drafted the manuscript. All authors critically revised the manuscript for important intellectual content. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. MW is a guarantor of the study.

**Funding** MW received funding from EU Horizon 2020 Research and Innovation programme (grant agreement number 101003589). A-MB is funded through her post as director of the Postgraduate Certificate in Qualitative Health Research Methods at the University of Oxford (no grant number). AJB's post has been funded by a research grant from the Economic and Social Research Council through the Antimicrobial Resistance Cross Council Initiative (reference: ES/P008232/1).

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** No data are available.

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