

## Research Paper

# Medicines management at home during the COVID-19 pandemic: a qualitative study exploring the UK patient/carer perspective

Sara Garfield<sup>1,2,3</sup>, Carly Wheeler<sup>1,2</sup>, Charles Boucher<sup>1,2</sup>, Mike Etkind<sup>1</sup>, Jill Lloyd<sup>1,2</sup>, John Norton<sup>1,2</sup>, Della Ogunleye<sup>1</sup>, Alex Taylor<sup>1,2</sup>, Marney Williams<sup>1</sup>, Tamasine Grimes<sup>4</sup>, Dervla Kelly<sup>5,6</sup> and Bryony Dean Franklin<sup>1,2,3</sup>

<sup>1</sup>Imperial College Healthcare NHS Trust, London, UK

<sup>2</sup>NIHR Imperial Patient Safety Translational Research Centre, Imperial College London, UK

<sup>3</sup>UCL School of Pharmacy, London, UK

<sup>4</sup>School of Pharmacy and Pharmaceutical Sciences, Trinity College Dublin, Dublin, Ireland

<sup>5</sup>School of Medicine, University of Limerick, Limerick, Ireland

<sup>6</sup>ULCaN, Health Research Institute, University of Limerick, Limerick, Ireland

\*Correspondence: Sara Garfield, UCL School of Pharmacy, 29-39 Brunswick Square, London WC1N 1AX, UK. E-mail: [s.garfield@ucl.ac.uk](mailto:s.garfield@ucl.ac.uk)

Received November 27, 2020; Accepted July 9, 2021.

## Abstract

**Objectives** To explore home medicine practices and safety for people shielding and/or over the age of 70 during the COVID-19 pandemic and to create guidance, from the patient/carer perspective, for enabling safe medicine practices for this population.

**Methods** Semi-structured interviews were carried out with 50 UK participants who were shielding and/or over the age of 70 and who used medicines for a long-term condition, using telephone or video conferencing. Participants were recruited through personal/professional networks and through patient/carer organisations. Participants were asked about their experiences of managing medicines during the pandemic and how this differed from previous practices. Data were analysed using inductive thematic analysis.

**Key findings** Patients' and their families' experiences of managing medicines safely during the pandemic varied greatly. Analysis suggests that this was based on the patient's own agency, the functioning of their medicines system pre-pandemic and their relationships with family, friends, community networks and pharmacy staff. Medicine safety issues reported included omitted doses and less-effective formulations being used. Participants also described experiencing high levels of anxiety related to obtaining medicines, monitoring medicines and feeling at risk of contracting COVID-19 while accessing healthcare services for medicine-related issues. Effects of the pandemic on medicines adherence were reported to be positive by some and negative by others.

**Conclusions** Pharmacy staff have a key role to play by establishing good relationships with patients and their families, working with prescribers to ensure medicines systems are as joined up as possible, and signposting to community networks that can help with medicines collection.

**Keywords:** COVID-19, pandemic, medicines, shielding, elderly

## Background

Medicines are the most common healthcare intervention. Prior to the COVID-19 pandemic, more than 8% of adult emergency hospital admissions and 25% of those for older adults were medication related, with increasing age and higher disease burden as key risk factors.<sup>[1,2]</sup>

During the COVID-19 pandemic, people self-isolating and housebound for long periods, due to age or 'extreme medical vulnerability', were potentially at increased risk of medicine-related problems. Potential issues included: disrupted routine healthcare services and supply chains; altered household mobility, wellbeing and support structures; restrictions on or reluctance to attending healthcare; and misinformation about medicines reported to affect the risk or severity of COVID-19 infection. These create additional challenges for medicines safety, at a time when prevention of harm is particularly important.

Little is known about changes to household medicines practices or safety during a pandemic. Previous studies in pandemics and epidemics<sup>[3-6]</sup> have not considered medicines safety from the viewpoint of patients/carers staying at home. In March 2020 in the UK, patients classified as 'extremely clinically vulnerable' were strongly advised by the government to 'shield', i.e. not leave their home. Pharmacists were paid a fee for home-delivery of medicines to patients on the shielding list. Those over 70 could access this service if other medical factors made them extremely clinically vulnerable. Community pharmacies experienced some staff shortages during this time where staff needed to shield or self-isolate.<sup>[7]</sup> The objectives of this study were to explore home medicines practices and medicines safety for people staying at home as much as possible during the COVID-19 pandemic and to create best practice guidance for medicines management during a pandemic from the patient/family carer perspective. The study was carried out in two countries: the UK and Ireland. This article presents findings from the UK.

## Methods

A qualitative cross-sectional study design was adopted, using semi-structured interviews. The study was approved by University College London Research Ethics Committee (reference: 18417.001) and the protocol was published.<sup>[8]</sup>

### Sampling and recruitment

A sample size of 50 was chosen due to anticipated diversity to support having sufficient information power.<sup>[9]</sup> Participants were recruited using a combination of convenience and purposive sampling to interview a range of participants regarding medical conditions, numbers of medicines, ages, genders, living alone versus with others, geography and ethnicities.

Adults, living in the UK, were eligible to participate if they met the Government's criteria for shielding during the COVID-19 pandemic and/or they were aged 70 years or more and were using at least one long-term medicine. Adults assisting in medicines management for an adult fulfilling these criteria were also eligible. Those under 18 years, unable to consent to interview, or without access to telephone or internet were excluded. One participant with limited English was included as she had a family member whom she asked to assist her during the interview.

Participants were recruited through the researchers' own personal and professional networks, patient and carer charities and organisations, and engagement with our patient and public involvement

(PPI) partners. Both social media and word-of-mouth were used to support recruitment. We kept a matrix of participants' demographic characteristics and medicines to enable us to target later recruitment towards less well-represented groups.

### Data collection

An interview topic guide was developed, and informed by a priori principles of routine lay medicines use<sup>[10]</sup> ([Supplementary Appendix 1](#)). Informed consent was received from all participants prior to participation. Where possible, this was through an electronic signature or a signed hard copy of the consent form being posted. Alternatively, verbal consent was invited by audio-recorded telephone or video call, as approved by the ethics committee.

Interviews were conducted remotely, between June and August 2020, either by telephone or video conferencing, depending on participant preference. Interviews were conducted by two research pharmacists working in hospital and academic settings (SG, BDF) and a health services researcher (CW). All had previous experience in conducting qualitative interviews. Interviews were audio-recorded, transcribed verbatim and anonymised. In two cases where the recording failed, detailed notes were made immediately after the interview.

### Data analysis

A constructivist-interpretive analysis approach was used, with the aid of NVivo. A coding framework was developed iteratively by SG, BDF, CW, TG and DK using Safety-I-II perspectives<sup>[11]</sup> and Schafheutle *et al.*'s medication work framework<sup>[10]</sup> as sensitising concepts.<sup>[8]</sup> A constant comparative technique enabled systematic organisation, comparison and understanding of similarities and differences in the data. An iterative approach was taken with analysis being conducted during data collection and emerging themes being explored further in remaining interviews. Nine interviews were checked for inter-coder reliability among SG, BDF and CW. The remainder of the interviews was then coded by SG or CW. Additionally, eight PPI representatives open-coded 48 interviews. Each PPI representative coded 12 interviews with each interview independently open-coded by two PPI representatives. Agreement of emerging themes was reached in an online nominal group session. The PPI analysis was subsequently integrated with that of the researchers and reviewed by all researchers and PPI representatives. All PPI representatives had previous training and experience in open coding.

The research was carried out and reported according to Standards for Reporting Qualitative Research.<sup>[12]</sup>

## Results

### Participants

Fifty people were interviewed (16 males, 34 females; mean age 68 years, range 26-93 years). Seven identified as being from a non-white ethnic group (comprising Caribbean British, Black African, Asian British, Asian, Sri Lankan, Indian and Chinese ethnicities). Participants were from England, Scotland and Wales, with six living in rural areas, one in a semi-rural area, and 43 in urban areas. Ten were living alone. Nine reported having a more dominant role in helping manage medicines for another adult who was over 70 and/or shielding, compared with managing their own medicines and focussed on their carer role during the interviews; seven of these were female. The number of medicines being taken ranged from 1 to 17.

## Diversity of experiences in managing medicines during the pandemic

We identified a wide range of experiences. Some participants reported there had been no change – either they already had delivery arrangements in place pre-pandemic which continued, or they continued to collect medicines from a local pharmacy during the pandemic. For others, there was a smooth transition from one supply system to another, such as a straightforward change to getting medicines delivered or collected by others. For others, there had been an initial ‘crisis’ period where obtaining medicines was very difficult at the beginning of the pandemic, which had then stabilised.

‘We moved from [pharmacy] which is impossible at the moment, you have to queue, etc. to another pharmacy. Obviously, there were basic problems at the beginning, not getting things or stuff, but it is all working itself out now.’ (participant 32)

For remaining participants, the pandemic served as a ‘tipping point’, exacerbating pre-existing challenges.

*So [pre-pandemic] when you go to collect [...] the things the doctor has been prescribing, the other stuff isn't due for repeat, so you are constantly having to go and chase those.’ [...]*

*‘[Post-pandemic] they would only have half the prescription, which they didn't tell you beforehand, and when we had to ask somebody to pick up the prescription and they would then come back with the slip saying please collect the other half next week [...] it meant asking somebody again [...] perhaps six, seven times in a couple of weeks, You can't keep asking favours all the time, it is quite embarrassing.’ (participant 22)*

## Factors affecting the diversity of experiences

Four themes seemed to account for much of this diversity. First, many participants described their own proactivity, determination and perseverance. Some expressed the view that they were in a more privileged position than others due to knowledge of the healthcare system, financial resources or ability to self-monitor their conditions.

Second, some participants reported having strong support from family, friends and/or community networks that helped them manage their medicines, mostly by collecting them.

Third, interview data suggested that support from community and hospital pharmacy staff was variable, with some participants describing very positive experiences and others negative (Box 1). Two key subthemes emerged regarding participants' experiences of

### Box 1: Participants' experiences of pharmacy services during the COVID-19 pandemic

#### Positive experiences

- ‘Well, I had to have a prescription during the course of the pandemic and so I submitted it in the usual way and they went to the chemist and then I actually rang the chemist, because I was in lockdown, and I rang the chemist, and I do actually know them very well and they know me very well [...] and they kindly said they would deliver it, which they did. It wasn't very difficult. I think I'm lucky because I've been going to them for a long time, they're not far away, I know them and there's an awful lot in having a personal rapport with people when they actually know who they're speaking to, it's a great help.’ (participant 35)
- ‘My local pharmacy have been good that they have been trying to deliver if they could. I don't know if I've been flagged up on their system but they phoned me and asked if I wanted it delivered and I said that it was okay, they could deliver to other people [instead] that might have needed it before, but they delivered it anyway.’ (participant 33)
- ‘The Friday morning before the lockdown happened on the Monday, he [pharmacist] rang me and said [name], you are [name of community organisation] aren't you ... and he said can I have the email addresses of the members so that I can give them, tell them that we wanted to do delivery and [I] also explained it's data protection, we couldn't give him but he could give me the leaflet [to disseminate] if he wanted.’ (participant 23)
- ‘And finally, two weeks ago, their community pharmacist based at the GP practice who does one day a week in the practice phoned me at home and she immediately understood the problem and kind of all the implications that meant for me as a partially sighted person who is supposed to be shielding at home, she said don't worry, I will sort it out and that was great and then the prescription came through for all my six meds, so that problem was solved’. (participant 48)

#### Negative experiences

- ‘Well, what happened was [name of pharmacy] originally used to[do] a ... free delivery, then they installed a payment per person for a delivery of £5 and because you know [name of wife] is a person that can't really go out because of her situation, so we were obliged to let them charge but we objected and within a reasonable period of time, they decided in their wisdom that they weren't going to charge and so far they haven't reintroduced the £5 charge.’ (participant 44)
- ‘No, they don't seem really keen to be delivering to people either, they try and make you...they say is there no friends or anything that you could ask?’ (participant 26)
- ‘Have you got your GP's letter? Have you got this? You must send somebody round to pick it up. We can't do this. I said “well, why, what's changed, I've had this twice?” You've only got to look at the prescription [interviewer name], to see it's all chest medicine, you know, what was the problem? So, anyway, I was getting a bit upset really. It made me feel like a nuisance.’ (participant 43).
- ‘I went all the way today to pick it up to be told it's not ready so I really haven't started taking them yet. [...] To be told yes you can come in, [...] I'm just so furious it wasn't ready.[...] If the hospital was just down the road I could say I could pick it up but I need a bus ride to go.’ (participant 12)
- ‘Then I came here one day to be told that she'd got a message, or they'd spoken to her, to say that her treatment, her chemo[therapy] treatment, was going to stop. So, obviously that caused a bit of distress because we didn't really understand it but then I was able to follow that up and send an email. So I think, again, the fact is I had emails for people I knew and then they got back in touch with us the following week to say “oh, that might have been wires crossed and dah, de, dah. So, that was restarted again.’ (participant 36)

pharmacy services: continuity and communication. Some reported having used the same local community pharmacy for many years with good relationships that continued through the pandemic. Others reported having to change from their usual community pharmacy at the beginning of the pandemic, either due to temporary closures of services or because the pharmacy was unable to deliver. In some cases, delivery services were organised through a separate team affiliated with a pharmacy chain and participants, therefore, lost continuity with their local provider. Communication between pharmacy staff and patients/carers, particularly where this was proactive, was also identified by participants as being important. However, many participants reported a lack of information or receiving misinformation. Loss of informal communication channels was reported by some as participants were not visiting the community pharmacy to collect medicines. Additionally, many reported challenges in contacting pharmacy staff at the beginning of the pandemic when they needed to rearrange medicines supplies or monitoring arrangements.

Fourth, the analysis suggested that the pre-pandemic functioning of the medicines management system affected its pandemic resilience. The most common issue identified was non-synchronised supplies of different medicines, caused by different order dates and lengths of supply, resulting in patients/carers having to obtain medicines several times each month. This made obtaining medicines more difficult while shielding. Additionally, some patients/carers obtained medicines from multiple places, such as from both community and hospital pharmacies. Others had different systems for medicines for different family members, with some being delivered and others not. In addition, when rearranging medicines supplies after the start of the pandemic, there was a 'disconnect' between prescribed medicines and those purchased over-the-counter.

*The problem I have got is I don't get prescribed [loratadine] as it is so cheap, I just buy it over-the-counter but as the pharmacy know I am shielding and everything, they really want it on a prescription, so they won't sell it to me. (participant 27)*

In addition to these four main themes, some participants reported roles that doctors had played by issuing prescriptions earlier, prescribing medicines that had been purchased over-the-counter pre-pandemic, or liaising with phlebotomy services to ensure continuity of medicines monitoring. Others reported that it was difficult to contact GPs at the start of the pandemic.

Analysis suggested that the above themes were more important in accounting for the diversity of experiences described than participants' demographic characteristics. However, people of working age seemed more likely to report major changes to their routines during shielding that affected continuity, for example, if they needed to change from collecting their medicines from a pharmacy near work to one near home. Taking a large number of medicines did not necessarily lead to more difficulties if medicines management had been working well pre-pandemic. However, having multiple prescribers of medicines, e.g. community and hospital, appeared to make changes during the pandemic more complex to navigate.

### Medicines outcomes related to the pandemic

Some participants described the negative effects of the pandemic on their health due to medicines issues experienced. For example, some had missed doses of medicines and others had been given less-effective formulations to avoid needing to use healthcare services.

*My medication was way overdue and these are immunosuppressants, you can't suddenly stop taking them, and*

*I hadn't had any for a couple of months. I was very achy (participant 37).*

Even where medicines-related issues did not cause identifiable physiological harm, participants described feeling very anxious as a result. This is related to obtaining supplies of prescription or over-the-counter medicines such as paracetamol, getting monitoring tests done or concern about catching COVID-19 when accessing pharmacies or other healthcare services.

*There was a lot of stress getting my medication. I didn't have enough [...] but the nurse did say, don't worry it is not disastrous [...] if you don't have quite enough for a week [...] but it is just a stress and the hassle if I am to get it all sorted out (participant 20).*

The pandemic appeared to have a range of effects on adherence. Some participants reported increasing adherence to ensure their long-term conditions were fully under control to help protect them against serious COVID-19 infection. Change of routine could have a positive or negative effect. Positive effects were reported where participants felt they had more time to focus on their medicines because they were less busy, and negative effects where medicine-taking was integrated into a daily routine that was disrupted.

*When I was forgetting to take my medicines before the pandemic, it was probably connected to having to rush out, [...] in the morning, and this [...] is kind of not a problem during shielding (participant 5).*

*I've struggled because I'm not going to work, my normal routine has been shot so I have regularly forgotten to take them in the morning (participant 3).*

Negativity linked to the pandemic could also lead to reduced adherence. In addition, two participants reported reconsidering the risk/benefit ratio of taking the medicines that resulted in them needing to shield.

For many participants, all types of medication-related work identified by Schafheutle *et al.*<sup>[10]</sup> changed or increased (Table 1).

## Discussion

Patients' and carers' experiences of managing medicines safely during the pandemic varied enormously, with some participants experiencing difficulties, others little change and a small minority experiencing some improvements. This variation appeared to be based on the patient's own agency, the functioning of their medicines system pre-pandemic, and their relationships with family, friends, community networks and pharmacy staff. Medicines safety issues included omitted doses and supply of less-effective formulations. There were mixed reports of the effects of the pandemic on medicines adherence. Aside from issues related directly to medicines safety, participants described experiencing high levels of anxiety about obtaining medicines, medicines monitoring and feeling at risk of contracting COVID-19 while accessing healthcare services to have medicines administered or monitored.

To the best of our knowledge, this is the first study to explore medicines safety for people who are shielding/over 70 during a pandemic from the patient/carer perspective. Our study was enhanced by the inclusion of a range of people in data analysis, including PPI representatives.

Our recruitment strategy sought to recruit as diverse a range of participants as possible and to address safety from both Safety-I and Safety-II perspectives,<sup>[11]</sup> with recruitment not being limited either

**Table 1** Changes to the types of medication-related work identified by Schafheutle *et al.*<sup>[10]</sup> during the pandemic

Type of work	Example of how affected by the pandemic
<b>Medication-articulation work:</b> Activities performed to maintain adequate stock and facilitate medicine-taking at instructed dose time	At the moment, yes my eldest daughter [organises our pill boxes], not the one [other daughter who is shielding] who sorts everything [else] out'. (participant 32)
<b>Surveillance work:</b> Monitoring supplies of medicines to ensure adequate personal stock	'You have to do [order] it a good 10–12 days before you run out [during the pandemic] so that's why it's good to have a Dosette [pill] box because you need to make sure [you order it in time], because it can take a time to come here and then we are being so careful that if any delivery comes, we are leaving it in our hallway for 3 days before we open anything.' (participant 6)
<b>Surveillance-articulation work:</b> Surveillance work creating a need for participants to act	'The only way it has changed a bit is that my husband was told to regulate one of the drugs. He was self-regulating one of the drugs to deal with a particular problem. [...] So, normally he would take this drug every week, but he was told to increase it according to his symptoms [...]. So, normally, out of the pandemic I wasn't so stressed out about it because he could easily go to the hospital and get guidance whereas at the moment you feel if you don't do as much as possible to keep yourself healthy and well, you know, it could be really problematic.' (participant 47).
<b>Informational work:</b> Clarification and checking information received from other network members and resolving medication concerns.	'The one that I stopped, it was pregabalin, and it was quite a complicated one because you've got to wean yourself off it slowly and so because I didn't have access to the [general practitioner's] surgery or the pharmacist really, because I was trying to stay at home, I looked it up on the internet and I did it myself slowly [...] I could've phoned the pharmacists, I could have phoned or emailed the surgery about it, but I knew that they were busy with other things and I thought I could manage that myself.' (participant 11).
<b>Emotional work:</b> Reassurance, reciprocation and prompting medicine-taking	'Because of this [the pandemic], she has lost what I call a keen interest in things [...] I have to make sure she takes the correct amount.' (participant 44)

to those experiencing or not experiencing medicines-related issues. Nevertheless, our findings suggest that many of our participants had a higher-than-average knowledge of the healthcare system. Those people we did not reach may have experienced more difficulties with their medicines during the pandemic. However, a survey carried out with people with disabilities<sup>[13]</sup> reported those with a higher educational level experiencing more difficulties with obtaining medicines during the pandemic. The reason for this remains unclear. Despite our relatively large sample, new themes were constantly emerging during data collection and we cannot be sure that our sample size led to theoretical saturation.<sup>[14]</sup> Despite efforts to increase the number of male participants, more females than males participated; this may be because they were more likely to assist with others' medicines.<sup>[15]</sup> In addition, these initial results are only from one country and may not be generalisable elsewhere. The findings from Ireland, once available, will shed further light on generalisability.

Laypeople's anxiety or difficulties about accessing healthcare were also reported during the Ebola and H1N1 epi/pandemics,<sup>[16–19]</sup> giving this finding cumulative validity. Recent research investigating laypeople's medication use during the COVID-19 pandemic has focussed on individual disease states rather than those housebound due to (extreme) medical vulnerability.<sup>[20–23]</sup> These studies considered broader aspects of disease management and did not explore lay medication-related experiences in-depth. This limits comparison with our findings. Nonetheless, variable effects on medication-adherence,<sup>[20, 22–24]</sup> challenge accessing healthcare or medication supplies<sup>[22–24]</sup> and health anxiety<sup>[21, 25]</sup> were commonly reported. While increased self-medication was reported during the Ebola epidemic,<sup>[17, 18]</sup> the studies undertaken during COVID-19 did not identify changes to self-medication patterns.<sup>[20–25]</sup> Increased self-alteration of prescribed medication, typically associated with concerns about risk of infection or severity of COVID-19 disease,<sup>[21–25]</sup> has been reported previously, consistent with our findings.

Our study findings contribute to the development of both the medication work framework<sup>[10]</sup> and a Safety-II approach,<sup>[11]</sup> i.e. understanding factors that create resilience in medicines systems. First, there were examples of all areas of medication work categorised by Schafheutle *et al.*<sup>[10]</sup> increasing as a result of the pandemic. This suggests that the pandemic added to the illness management burden and may have made it more difficult to provide care that was minimally disruptive to patients' and carers' lives.<sup>[26]</sup> We also identified a considerable increase in medicines-related anxiety that did not fall under Schafheutle *et al.*'s<sup>[10]</sup> initial definition of emotional work, suggesting it could be helpful to broaden this definition. Second, in relation to resilience, Fylan *et al.*<sup>[13]</sup> identified the important role of patients and their families in creating resilience in medicines management after hospital discharge. Our study further suggests that this role is also important in other situations, such as during a pandemic, and that it can be extended to wider community networks. As the pandemic was a novel situation, participants may have been unable to draw on past experiences. However, they drew on anticipatory resilience<sup>[27]</sup> (proactively making a decision or taking a course of action that has an expected consequence in a given situation—such as ordering medicines earlier to maintain supply) and responsive resilience<sup>[27]</sup> (reacting effectively when a situation changes—such as setting up/accessing community delivery services). Vos *et al.*<sup>[28]</sup> identified nurses as an important source of medicines resilience; our study suggests that this can be extended to pharmacy staff. Our analysis further suggests that continuity and communication were two key elements of resilience in medicines systems during times of change.

## Implications for Practice and Policy

The findings suggest that pharmacy staff can make a significant difference during a pandemic, both through proactive, empathic

communication with patients/carers and by maintaining continuity in pharmacy services where possible. Our study did not find examples of misinformation regarding medicines themselves but did reveal examples of misinformation and/or miscommunication about services to access medicines, suggesting this as an important area for pharmacy staff to focus on.

Pharmacy staff may not be able to meet all patients'/carers' expectations regarding delivery, without reimbursement for this service. However, a clear explanation and signposting of patients/carers to alternative forms of delivery could be a potential solution, in addition to encouraging patients/carers to order medicines earlier than usual (see [Supplementary Appendix 2](#) for advice for patients/carers co-designed with PPI representatives). Pharmacy staff can also help by liaising with GP practices to help ensure patients' medicines request dates are synchronised to avoid multiple pickup/delivery each month and that prescriptions are issued early enough to allow extra time for delivery. Changing to two-monthly prescriptions may also be appropriate. These recommendations are also potentially helpful for housebound patients beyond the pandemic. We believe that the key factors that are important to patients regarding medicines management are likely to be consistent across countries although systems for addressing these may vary.

## Conclusions

Our findings suggest considerable diversity in patients'/carers' experiences of medicines management when staying at home during the COVID-19 pandemic, and that this is partly linked to the provision of pharmacy services. Pharmacy staff can play a key role by establishing good relationships, maintaining continuity in service provision, working with prescribers to ensure medicines ordering dates are as synchronised as far as possible, and facilitating medicines delivery.

## Supplementary Material

Supplementary data are available at *International Journal of Pharmacy Practice* online.

## Acknowledgements

We acknowledge Fran Husson's contribution to highlighting the importance of this research area and to the dissemination of key messages to members of the public.

## Author Contributions

TG and DK conceived the study with subsequent adaption for the UK context by BDF and SG. TG, DK, SG, BDF, CW, JN, ME, MW, JL and AT contributed to the study design. SG, BDF, and CW collected the data. All authors contributed to data analysis. SG and CW drafted the paper. All authors were involved in editing the manuscript and approved the final version.

## Funding

This work was supported by the National Institute for Health Research (NIHR) Imperial Patient Safety Translational Research Centre (grant number SF003). This report presents independent research. The views expressed in this publication are those of the authors, not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

## Conflict of Interest

None declared.

## References

- Ahern F, Sahn LJ, Lynch D *et al.* Determining the frequency and preventability of adverse drug reaction-related admissions to an Irish University Hospital: a cross-sectional study. *Emerg Med J* 2014; 31: 24–9. <https://doi.org/10.1136/emered-2012-201945>
- Hamilton H, Gallagher P, Ryan C *et al.* Potentially inappropriate medications defined by STOPP criteria and the risk of adverse drug events in older hospitalized patients. *Arch Intern Med* 2011; 171: 1013–9. <https://doi.org/10.1001/archinternmed.2011.215>
- Bali S, Stewart KA, Pate MA. Long shadow of fear in an epidemic: fearonomic effects of Ebola on the private sector in Nigeria. *BMJ Glob Health* 2016; 1: e000111. <https://doi.org/10.1136/bmjgh-2016-000111>
- Gasink LB, Linkin DR, Fishman NO *et al.* Stockpiling drugs for an avian influenza outbreak: examining the surge in oseltamivir prescriptions during heightened media coverage of the potential for a worldwide pandemic. *Infect Control Hosp Epidemiol* 2009; 30: 370–6. <https://doi.org/10.1086/596609>
- McLean KE, Abramowitz SA, Ball JD *et al.* Community-based reports of morbidity, mortality, and health-seeking behaviours in four Monrovia communities during the West African Ebola epidemic. *Glob Public Health* 2018; 13: 528–44. <https://doi.org/10.1080/17441692.2016.108262>
- Brown JD, Vouri SM, Manini TM. Survey-reported medication changes among older adults during the SARS-CoV-2 (COVID-19) pandemic. *Res Social Adm Pharm* 2020; 17: 1478–82. [https://doi.org/551-7411\(20\)31190-6](https://doi.org/551-7411(20)31190-6).
- Wickware C. Up to 15% pharmacy staff off work in some chains owing to COVID-19. *Pharm J* 2020; 304. <https://doi.org/10.1211/PJ.2020.20207875>
- Grimes TC, Garfield S, Kelly D *et al.* Household medication safety practices during the COVID-19 pandemic: a descriptive qualitative study protocol. *BMJ Open* 2020; 10: e044441. <https://doi.org/10.1136/bmjopen-2020-044441>
- Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016; 26: 1753–60. <https://doi.org/10.1177/1049732315617444>
- Schafheutle EI, Fegan T, Ashcroft DM. Exploring medicines management by COPD patients and their social networks after hospital discharge. *Int J Clin Pharm* 2018; 40: 1019–29. <https://doi.org/10.1007/s11096-018-0688-7>
- Carson-Stevens A, Donaldson L, Sheikh A. The rise of patient safety-II: should we give up hope on safety-I and extracting value from patient safety incidents?: comment on "False Dawns and New Horizons in Patient Safety Research and Practice". *Int J Health Policy Manage* 2018; 7: 667. <https://doi.org/10.15171/IJHPM.2018.23>
- O'Brien BC, Harris IB, Beckman TJ *et al.* Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014; 89: 1245–51. <https://doi.org/10.1097/ACM.0000000000000388>
- Fylan B, Armitage G, Naylor D *et al.* A qualitative study of patient involvement in medicines management after hospital discharge: an under-recognised source of systems resilience. *BMJ Qual Saf* 2018; 27: 539–46. <https://doi.org/10.1136/bmjqs-2017-006813>
- Saunders B, Sim J, Kingstone T *et al.* Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018; 52: 1893–907. <https://doi.org/10.1007/s11135-017-0574-8>
- Cares UK 10 facts about women and caring in the UK on International Women's Day. <https://www.carersuk.org/news-and-campaigns/features/10-facts-about-women-and-caring-in-the-uk-on-international-women-s-day> (8 April 2021, date last accessed).
- Haroon SMM, Barbosa GP, Saunders PJ. The determinants of health-seeking behaviour during the A/H1N1 influenza pandemic: an ecological

- study. *J Public Health* 2011; 33: 503–10. <https://doi.org/10.1093/pubmed/fdr029>
17. McLean KE, Abramowitz SA, Ball JD *et al.* Community-based reports of morbidity, mortality, and health-seeking behaviours in four Monrovia communities during the West African Ebola epidemic. *Glob Public Health* 2018; 13: 528–44. <https://doi.org/10.1080/17441692.2016.1208262>
  18. Bali S, Stewart KA, Pate MA. Long shadow of fear in an epidemic: fearonomic effects of Ebola on the private sector in Nigeria. *BMJ Glob Health* 2016; 1: e000111. <https://doi.org/10.1136/bmjgh-2016-000111>
  19. Yamanis T, Nolan E, Shepler S. Fears and misperceptions of the ebola response system during the 2014-2015 outbreak in Sierra Leone. *PLoS Negl Trop Dis* 2016; 10: e0005077. <https://doi.org/10.1371/journal.pntd.0005077>
  20. Samargandy SA, Al Garmi TA, Almoghairi A *et al.* Effect of COVID-19 pandemic on the cardiac outpatients' perception of seeking medical advice. *J Saudi Heart Assoc* 2020; 32: 377–82. <https://doi.org/10.37616/2212-5043.1094>
  21. Mir N, Cheesbrough J, Troth T *et al.* COVID-19-related health anxieties and impact of specific interventions in patients with inflammatory bowel disease in the UK. *Frontline Gastroenterol* 2021; 12: 200–6. <https://doi.org/10.1136/flgastro-2020-101633>
  22. Rathi M, Singh P, Bi HP *et al.* Impact of the COVID-19 pandemic on patients with systemic lupus erythematosus: observations from an Indian inception cohort. *Lupus* 2021; 30: 158–64. <https://doi.org/10.1177/0961203320962855>
  23. McAuley H, Hadley K, Elneima O *et al.* COPD in the time of COVID-19: an analysis of acute exacerbations and reported behavioural changes in patients with COPD. *ERJ Open Res* 2021; 7: 00718-2020. <https://doi.org/10.1183/23120541.00718-2020>
  24. Hassen LM, Almaghlouth IA, Hassen IM *et al.* Impact of COVID-19 outbreak on rheumatic patients' perceptions and behaviors. *Int J Rheum Dis* 2020; 23: 1541–9. <https://doi.org/10.1111/1756-185X.13959>
  25. Georgakopoulos JR, Mufti A, Vender R *et al.* Treatment discontinuation and rate of disease transmission in psoriasis patients receiving biologic therapy during the COVID-19 pandemic: a Canadian multicenter retrospective study. *J Am Acad Dermatol* 2020; 83: 1212–4. <https://doi.org/10.1016/j.jaad.2020.07.021>
  26. Leppin AL, Montori VM, Gionfriddo MR. Minimally disruptive medicine: a pragmatically comprehensive model for delivering care to patients with multiple chronic conditions. *Healthcare* 2015; 3: 50–63. <https://doi.org/10.3390/healthcare3010050>
  27. Larcos G, Prgomet M, Georgiou A *et al.* A work observation study of nuclear medicine technologists: interruptions, resilience and implications for patient safety. *BMJ Qual Saf* 2016; 26: 466–74. <https://doi.org/10.1136/bmjqs-2016-005846>
  28. Vos J, Franklin BD, Chumbley G *et al.* Nurses as a source of system-level resilience: secondary analysis of qualitative data from a study of intravenous infusion safety in English hospitals. *Int J Nurs Stud* 2020; 102: 103468. <https://doi.org/10.1016/j.ijnurstu.2019.103468>