Original Article

Exploring views and recommendations from travellers and their representative officers about components of an acceptable digital medication adherence intervention: A Patient and Public Involvement exercise

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Introduction

Gypsy Roma Travellers (GRTs) are significantly more likely to have a Long Term Health Condition (LTHC) and suffer poorer health than the general population. Their life expectancy has been estimated to be between 10 and 12 years less than the general population (Lane, Spencer & Jones, 2014). Within the UK there are officially 58,000 GRTs (Office for National Statistics, 2014), although the true figure is probably significantly higher (Rhodes, 2005), as many GRTs do not disclose their status for fear of discrimination (Heaslip, Hean & Parker, 2016). The National Institute for Health Research also highlighted the need to engage traveller communities in health improvement interventions (Carr et al., 2014).

Medication non-adherence is very common among patients with LTHCs (Kleinsinger, 2018). Adherence presumes an agreement between prescriber and patient about the prescriber's recommendations (NICE, 2009). In England, more than 15 million people have a LTHC, which is defined as *–one health condition that generally lasts a year or longer and impacts on a person's life* (NICE, 2020).

According to a World Health Organisation (WHO) report, inadequate medication adherence averaged 50% among patients with chronic diseases/LTHCs (Sabaté, 2003) and represented a significant problem that led to increased morbidity and mortality, as well as increased healthcare costs (Cramer et al, 2008; Col, Fanale & Kronholm, 1990). Increasing awareness about adherence to prescribed medications to manage LTHCs can be very important, as these conditions are by far the leading causes of morbidity and mortality (Simon et al., 2011; WHO, 2005).

To address this issue, there is increasing interest in the use of digital interventions to support medication adherence and improve self-management of treatments (Patel, Jones, Adamson, Spiteri & Kinmond, 2016; Morrison et al., 2015). Several recent reviews (Armitage, Kassavou & Sutton, 2020; Kassavou & Sutton 2018) also demonstrated positive effects of digital medication adherence interventions on patients' adherence. Various studies have also indicated that interactive voice response and SMS (Kassavou et al., 2020) foster medication adherence through telephone-delivered education and interactive reminders can improve medication adherence in patients with diabetes (Arora, Peters, Agy & Menchine 2012; Lyles et al., 2013; Williams, Lynch, Knapp & Egede, 2014). These digital health strategies provide interactive communication that is timely and

patient-centered (Conway & Kelechi, 2017). However, no literature was found related to digital interventions to support medication adherence for the GRT community.

In terms of adherence to prescribed medications in the GRT population, very little information was found. For instance, a review report (Cemlyn et al., 2009) demonstrated that literacy problems within the community greatly increase the risks of changing the dose (e.g. accidental overdose, inappropriate dosage) or not taking their prescribed medication (e.g. giving anti-depressants to others). This issue links with health literacy, which is defined as - *the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions* (Institute of Medicine, 2004).

Overall, no literature was found related to exploring views about a digital medication adherence intervention in the GRT population. Thus, to explore this area initially, a Patient and Public Involvement (PPI) project was set up with a group of travellers and their representatives from key voluntary and statutory sector agencies in the district and the County Council (hosted by the district council, for more information, please see: South Cambridgeshire District Council, 2010) in the East of England to inform future research about medication adherence in the GRT community. This project aimed to explore views about barriers regarding medication adherence and to generate recommendations regarding potential components of a digital intervention.

Method

Face-to-face recruitment of the GRT participants (n=6, 2 males, 4 females) was conducted through word of mouth of a community nurse. These participants were provided financial incentives (i.e. a £10 voucher to each) to take part in interviews. Interviews (10-20 min approx.) were conducted at a community hall during drop-in sessions, using a semi-structured interview guide (box 1). One of the purposes of the interview guide was to obtain views and recomendations about potential components of a mobile application which they think would suit their needs and how that will support them to adhere to their prescribed medications. The participants had various types of LTHCs, e.g. chronic pain, hypertension, diabetes and asthma. During interviews, participants were shown images related to most of the questions asked (box 2).

Five representative officers were interviewed (3 via phone call and 2 via face to face) using a semi-structured interview guide (box 3). These representatives particularly provide support to the GRT population related to reading and writing letters related to domestic/household activities, finding any required information via telephone, making and attending health care appointments, exploring job opportunities, accessing benefits as well as health care and schooling. Each interview was 20-40 minutes long. Interviews with both groups were conducted by a behavioural science researcher (KA), recorded on a digital voice recorder with participants' permission and transcribed by a trustworthy transcription service.

Analysis

Thematic analysis, using a deductive approach to identify patterns and themes across the data set (Braun & Clarke, 2006) was applied to analyse the data emerging from the interviews. The transcripts were read through several times by the first author to obtain a good sense of the entire data followed by the co-authors, who independently noted emerging patterns in themes, on which there was a close agreement.

Box 1 – GRT participant interview guide

1. Could you tell me what prescribed tablets you are taking nowadays?
2. Could you tell me about your current routine of taking prescribed tablets (e.g. morning, afternoon, evening)?
3. Do you sometime forget taking them, if yes what might be the reason/s?
4. Do you have smart phone, if yes, do you use an app regularly?
5. If yes, looking at page 1 - top 3 images of medication, which one image you would prefer to see in your medication reminder app and why?
6. Looking at page 1 - bottom 3 images, which one image you would prefer to see in your medication reminder app and why?
7. Looking at page 2, which reminder notification messages you would prefer to receive and why?
8. Page 3 – which monthly calendar you would prefer and why?
9. Page 4 – blank space – what other messages/information or anything else you would like to receive in your app message, please draw or write or explain (if participants cannot write, then researcher can write them down)?
10. What benefits you can think of using an app like this?
11. What concerns comes in your mind by using an app like this?
12. Would you accept a recommendation from your nurse to download an app like this?
13. If yes, what makes you think to accept these recommendations?

Box 2- Images used with the interview guide for the GRT participants

Page 1: Images of medications

Box

Pill packet

Image source: *https://www.euroclinix.net/en/high-blood-pressure/lisinopril*

Box and pill packet

Image source: https://www.bbukltd.com/products/lisinopril-tablets/

Symbol of pill/capsule etc

Upload your own photo of medication

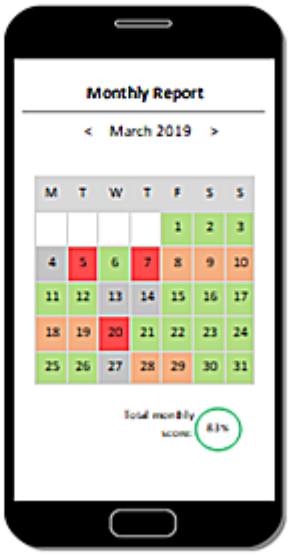
No image

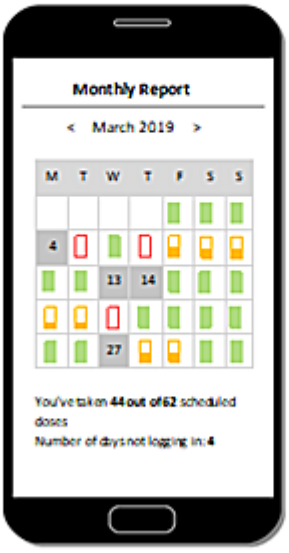
Page 2: Reminder notification messages

Image source: Screenshot from My MedSchedule app

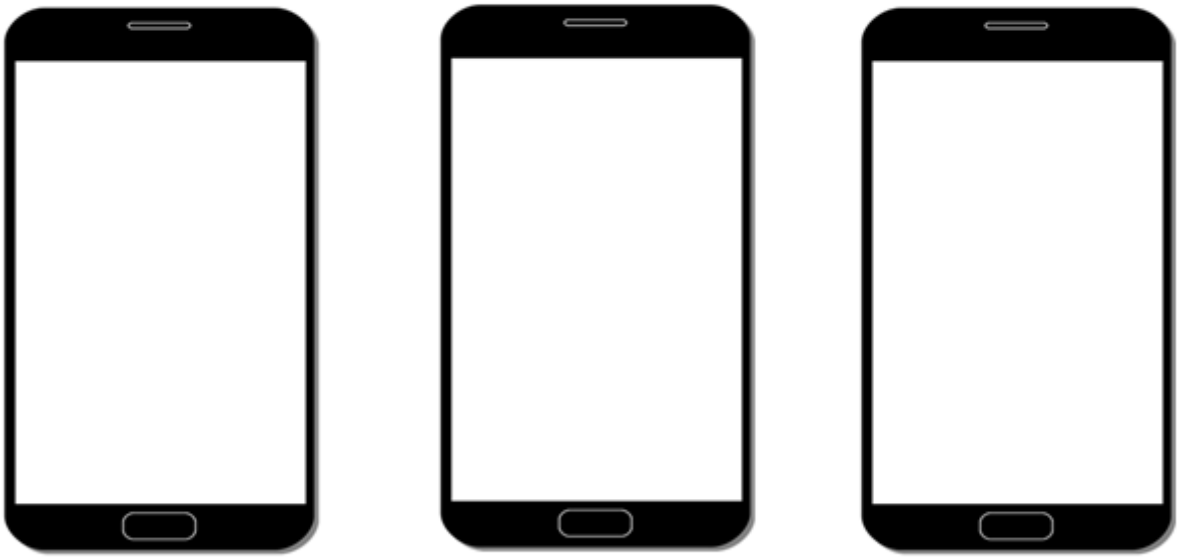
https://play.google.com/store/apps/details?id=com.medactionplan.mymedscheduleplus&hl=en

Page 3: Feedback of doses taken – Monthly calendar





Page 4: Blank images



Box 3 – Traveller representative officers' interview guide

General questions:

1. How long have you been working with travellers?
2. What is this population's general lifestyle? Probe related to schooling in childhood, socio-economic status (e.g. jobs, education levels, source of income etc.)
3. What issues they face in day to day life based on your experiences of working with them? Probing (can you provide more information or examples about each issue in bit more detail, e.g. health inequalities etc…)
4. How many people (e.g. majority or minority) are diagnosed roughly with long term health conditions?
5. What are those conditions based on your experiences?
6. What age groups are normally diagnosed with long term health conditions?

Specific questions:

1. How usually people remember taking those prescribed medications?
2. Are there any barriers adhering to the prescribed medications? If yes, what are those barriers/issues/challenges you have come across from this community? Probe- any beliefs affecting taking medications….
3. How familiar this population is (who use prescribed medications for long term health conditions) in terms of using or being familiar with technology.
4. What kind of approach you would recommend to support these people to take their prescribed medications? Probe – as you mentioned that some people use app like……., what kind of app would be suitable for this population (with no/lack of reading and writing skills) and how it could be facilitated to them and by who?
5. Any other recommendations to support this population to take prescribed medications?
6. Anything you would like to add on?

Results

The analysis of the data from all participants, revealed five themes (mentioned below). Please see all quotes related to themes in table 1 (supplementary file).

1-Barriers to adherence to medications

Participants mentioned various barriers to adhering to medications, including forgetfulness and literacy issues.

1.1-Forgetfulness

Some participants (*300081m, 300082f, Rep 2*) described various reasons for not remembering to take medications. For instance, medications kept out of view, being concerned about family members' situations, confused/hectic lifestyle.

1.2-Illiteracy/Low health literacy

In terms of low health literacy, one of the representatives pointed out that use of complicated words/medical terms in letters sent by healthcare services makes it very hard to understand the information by people who can only understand basic English. A similar issue exists during appointments to understand the provided information despite both parties speaking same language (*Rep 3*).

A major barrier to adherence seemed to be illiteracy among people with LTHCs. As mentioned by various GRT participants (300081m, 300083m, 300085f) that they are unable to read and write and images/symbols help them to understand any messages/information related to medications.

Sometimes, illiteracy can lead to life threatening and costly situations due to taking wrong medications, as described by one representative (Rep 4). Due to illiteracy some people seemed to identify their medications by the packaging colour rather than the names. They also seemed to have a lack of understanding of the reason for being prescribed medications if they had to take different types of medications for different purposes (*Rep 4, Rep 5*).

One of the other major barriers due to illiteracy was not understanding/knowing about the side effects, as participants seemed to be unable to read the leaflet provided with the medication. Therefore, they might start overdosing when in severe pain through thinking that taking more medications will relieve the pain quickly. Such situations can be life threatening. (*Rep 5*).

2-Facilitators to medication adherence

Younger family members often reminded the older ones (in the form of social support) because they knew the purpose and recommended timings of taking the medications (*Rep1, Rep 3, Rep 5*). Another strategy mentioned by a representative to remember taking prescribed medications was the 'dossette boxes', provided by the practitioners on request (*Rep 4*).

3-Suggestions for a medication adherence app

3.1-Content

Participants (*300081m, 300082f, 300083m, 300084f, 300085f, 300086f*) provided suggestions related to the content of a medication adherence app that they would find helpful and was related to their needs (by looking at the images, box 2). All of them chose an image of a medication box (to appear in the reminder app) as it reminded them about their medications.

3.2-Notification messages

Similarly, in regards to receiving notification messages, participants (*300081m, 300082f, 300083m, 300084f, 300085f, 300086f*) chose symbols of tablet/capsules and medication box image because such images were considered very helpful in remembering to take medications.

3.3-Monthly calendar

In terms of receiving a monthly report related to medication adherence, participants were shown two images (Box 2, page 3). They chose the first image because it was colour coded (similar to a traffic light system), with green meaning doses taken and red meaning missed doses. Colour coding seemed to help them to understand the monthly report

(*300081m, 300082f, 300084f, 300085f*). However, one participant (*300086f*) preferred percentage of doses taken (rather than colour coding) as it could help her to re-order the prescribed medications based on what she required rather than ordering a full prescription.

4. Benefits and concerns for using a medication adherence app

Benefits: A number of benefits of using a simple medication adherence app were identified by the participants (*300081m, 300082f, 300083m, 300084f, 300085f*), e.g. being informed to take prescribed medications at the right time regularly, useful for people with low health literacy and those who forget, save young family members' time to remind the elderly members and clicking on a symbol 'tick' on the app message (after taking medications) can be a motivational strategy for some people.

Concerns: Several concerns were expressed by participants (*30081m, 300086f, 30084f*), e.g. Wi-Fi issues, confidentiality issues, e.g. other people getting access to their information and not having knowledge/understanding about using apps.

5. Other suggestions/approaches

Participants (*300081m, Rep 1*) also suggested that a basic medication adherence app consisting of a medication box image with time or video-based messages would be easy to understand due to low reading skills. One of the representatives (*Rep 4*) highlighted an important issue of disseminating the information related to a medication adherence app among this population. Increasing awareness about the medication adherence app's accessibility may help people to download it. Furthermore, it was suggested (*Rep 4*) that leaflets should be designed with simple instructions about how to download the medication adherence app. Such leaflets could be provided by the practitioners to take home, and family members (or other people) could help patients to download the app.

Other suggestions were a) to use a voice activated system in the app to provide responses (as on Google) to increase engagement b) to conduct a feasibility trial in this population to test an app designed to meet the needs of this population *(Rep 4*). In terms of the content of the app, it was suggested to add names/pictures of medications and prescribed timings of taking such medications related to users' daily activities/tasks (*Rep 5*).

Similarly, another participant (*300082f*) suggested that a reminder message appearing on the phone in the form of a sound alarm with flashing pictures of medications would be easy for people (with low/limited reading skills) to understand. People seemed to know their medication boxes and seeing a picture of those boxes would remind those who forget to take their medications.

Furthermore, one representative (*Rep 2*) suggested that sending simple and short text messages could be useful for those people who only have a basic mobile phone and very limited reading skills. She emphasised the importance of demonstrating and practising the procedure in detail, so that they understand and know what to expect. Spending time to help them understand the content of the message (e.g. what it will look like) will help them understand the importance of taking prescribed medications and will more likely meet their expectations when they receive the text message.

Representatives (*Rep 1, Rep 2*) described various other approaches to support people taking prescribed medications. For instance, health care professionals can provide informational support tailored to patients' understanding and needs and emphasise the importance of taking medications as prescribed. In terms of sending medication reminders via text messages, it is important to check that they match participants' level of reading skills, and to ensure that they understand the messages.

An important point raised by one representative (Rep 3) was that individualised and tailored

approaches might be more effective than a generic approach. For example, for some people, setting an alarm might work due to its sound. For others, drawing pictures of the moon and sun to represent day and night time of taking medications could be helpful for those with reading difficulties (unable to read). Similar approaches were mentioned by other representatives (*Rep 4, Rep 5*), e.g. setting an alarm on mobile phones or wrist watches and using picture-based information to remind people to adhere to prescribed medications.

Discussion

Participants' perspectives highlighted several barriers to medication adherence. Having low health literacy seemed to affect not only participants' medication adherence behaviour but also their health. Findings from previous studies show that patients' health literacy has a significant impact on patients' medication adherence (Mosher, Lund, Kripalani, & Kaboli, 2012; Osborn, Paasche-Orlow, Bailey & Wolf, 2011) and related health care utilization (Koh, Baur, Brach, Harris & Rowden 2013).

Poor health literacy increases lack of confidence and fear of being scorned for ignorance and makes it more difficult for patients to ask for clarification when explanations from practitioners are not understood. These difficulties appear to contribute to reduced compliance with prescribed treatments (Parry et al., 2004). Thus, a council report highlighted the need to consider any literacy difficulties in the GRT community (Hutton, 2011). In general, a systematic review assessed eHealth interventions targeting health literacy and found that the interventions using technology (compared to control interventions) reported significant outcomes or showed promise for future positive outcomes regarding health literacy in a variety of settings, for different diseases, and with diverse samples (Jacobs, Lou, Ownby & Caballero, 2014). In another review (including some web-based interventions), findings demonstrated that health literacy interventions are more likely to be successful if they are theory-based, are multi-faceted and use person-centered operational components such as cultural appropriateness, tailoring, skills building, goal setting and active discussions (Stormacq, Wosinski, Boillat & Van den Broucke, 2020). In short, some of the effective components of digital interventions can be utilised to overcome health literacy in the GRT community.

In terms of designing a simple medication adherence app, participants suggested using a picture of medication boxes and a colour-coded monthly calendar. In addition, they also provided other suggestions to address the issue of poor health literacy, e.g. sound alarms, picture of medications with sound, voice activated app and design the app tailored to people's needs. Some of these suggestions are also supported by a council report (Hutton, 2011), in which a study conducted in Scotland found that most Gypsy/Travellers would prefer information to be provided in audio/visual formats. Additionally, use of plain English is considered important to engage with this community. A report of the Department of Health (Parry et al., 2004) also suggested that materials (e.g. health service information) should be provided in the form of audiotapes or audio CDs for a population at severe educational disadvantage and with poor levels of reading skills. Similar information to tackle health literacy (via non-written formats) are provided in the policy implementation guidance for healthcare practitioners on working effectively with Gypsies and Travellers (Travelling to Better Health, 2015).

In terms of using a medication adherence app in the future, participants also mentioned various benefits (e.g. increase awareness to take medications, send reminders) and concerns (e.g. fear of other people holding information, Wi-Fi issues). These findings (as well as various components related information, e.g. content and

format) can be useful for future research to take into consideration when designing a simple medication adherence app.

The analysis has highlighted some important barriers related to medication adherence and overcoming strategies for the GRT population. The findings from this project can increase awareness among researchers, policy-makers, public health physicians and clinicians to provide support to this population related to medication adherence. No qualitative study was found in the literature search related to this area. Participants' suggestions are a valuable addition to the literature and to improving current services particularly related to medication adherence interventions for populations with poor health literacy. It is recommended that, when developing interventions, it would be helpful to consult and collaborate with those already working effectively in the GRT community, to ensure that work is carried out in a consistent and flexible manner, to provide top-down support in order to promote a consistent response to the GRTs' needs (Hutton, 2011).

Overall, the strength of this project lies in its qualitative methodology, e.g. use of interviews was potentially more beneficial in terms of maintaining the privacy of individual health issues and suggestions as well as gaining richer data in comparison to quantitative methodology. In terms of limitations, it is important to note, that representatives provided more in-depth information based on the questions asked in comparison to the GRT participants, thus results seemed to be dominated by the representatives' perspectives. GRT participants seemed to be hesitant to talk to provide in-depth information, probably due to literacy issues/lack of knowledge. This project was conducted for PPI purposes (with a small number of participants) rather than for research. Thus, it is recommended that a more comprehensive qualitative research project be undertaken in the future.

Overall, the current project provides distinctive information related to medication adherence barriers and recommendations related to a digital intervention from the traveller PPI group, which require attention. It is important to explore these findings further via more comprehensive research followed by implementing a feasible, tailored and culturally sensitive digital intervention to support medication adherence for this population. Involving multiple agencies (e.g. healthcare, social, education and council services) in such interventions could be very useful in terms of increasing awareness about such health behaviour related issues. In terms of service improvements, there is a need to improve access and services for the GRT population as well as improving the cultural competence of health service staff.

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