

# The Logics of Invited and Uninvited Material Participation: Bringing Blood Pressure Self-Monitoring Into the Clinic

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## Abstract

This paper addresses debates concerning the 'participatory turn' in healthcare. It focuses on the case of blood pressure self-monitoring, understanding this as a form of patient participation at the level of individual care. Drawing and expanding on the work of Marres and Wynne and their notions of material participation and of uninvited engagement, we examine how patients' home blood pressure self-monitoring is incorporated into clinical care, how the materials of blood pressure self-monitoring mediate participation and how we might characterise the practices of participation found within everyday clinical care. Our analysis makes new conceptual links, suggesting that, in this context, invited participation appears to align with participation made easy, while uninvited participation involves more invested, more engaged participation. We offer two further developments of these concepts. First, we trouble characterisations of invited and uninvited participation as distinct and separate, observing movement between these. Second, through applying the logics of material participation in a new context, everyday clinical practice, we suggest that the logic of participation made easy might be extended beyond lay people, to apply to professionals as well. Our analysis illustrates how materials are mobilised to facilitate invited and uninvited participation within the context of the on-going asymmetries in doctor patient relationships.

**Keywords:** Material participation, Uninvited participation, Patient participation, Self-monitoring, Blood pressure, Primary care.



## Introduction

Self-care, including self-monitoring, is seen as a key element of the so-called 'participatory turn' (Prainsack, 2017) in health care. This emphasises public and patient involvement in different arenas including policy, research, service review and individual health care (Sinding et al., 2012; Stewart, 2016; Prainsack, 2017; Nielsen and Langstrup, 2018). At the level of individual health care, patient participation is imagined to contribute not only to health service efficiencies in the face of growing demand, but also to empowering patients to contribute to, and thereby improve, their care experiences and outcomes (Sinding et al., 2012; Prainsack, 2017; Jones, 2018). While the active participation of patients continues to be "tirelessly promoted" in policy and commercial discourse (Nielsen and Langstrup, 2018: 260), social scientists have critiqued this in a number of ways. They have argued that ideas of patient involvement and self-care found in this discourse embed individualised notions of human action, have argued for a more relational understanding of autonomy and called for greater attention to the wider infrastructures of care (e.g., Mol, 2008; Danholt and Langstrup, 2012; Sinding et al., 2012). They have also drawn attention to structural and political influences on health, as well as the social function of medicine (e.g., Pilnick and Dingwall, 2011; Jones, 2018).

In policy discourse, the promotion of self-care and self-monitoring has been linked to the development of digital innovations. For example, the UK Topol Review (Topol, 2019) envisions that smartphone apps, sensors and wearables for diagnostics will help to track 'vital signs' such as heart rate, respiratory rate, oxygen and blood pressure, and that, within two years of launching, the new National Health Service (NHS) App will allow people to upload data from their 'wearable and lifestyle apps'. The report rehearses the language of patient empowerment and participation, suggesting, for example, that making patient-generated data clinically useful will "empower patients to manage their own health or seek appropriate health support" (Topol, 2019: 10). These arguments represent a contemporary iteration of an established narrative about the empowering effects of new technologies in healthcare, long critiqued by social science and

STS scholars (e.g., Oudshoorn, 2008). In this paper, we continue this critique by considering blood pressure self-monitoring as a form of patient participation and exploring how this is incorporated into clinical care.

In focusing on the processes of participation, we turn to insights from STS in particular. Reviewing this scholarship, Chilvers and Kearnes (2020: 253-254) observe a move from "a dominant imaginary of participation as confined to discrete, isolated, and ephemeral events and time-spaces" and concern with the development of "'formalized mechanisms of voicing" (Michael, 2012: 530) to understandings that increasingly "encompass material, embodied, private, digital, uninvited, everyday, mundane forms of public engagement" (Chilvers and Kearnes, 2020: 355). In our analysis of the practices of participation associated with blood pressure self-monitoring we draw on two aspects of Chilvers and Kearnes' characterisation of participation: uninvited and material participation

The notion of uninvited public engagement was a response to scholarship focussed on formal and discrete engagement events. Wynne (2007) proposes that uninvited public engagement arises in response to these expert-led interventions. Such interventions have an "implicit politics-as to what is salient and what is not salient" and "uninvited forms of public engagement are usually about challenging just these unacknowledged normativities" (Wynne, 2007: 107). Such uninvited participation tends to be imagined as coordinated and collective campaigns or actions (Wynne, 2007; Wehling, 2012). Stewart's (2016) work on participation in health systems, however, identifies uninvited participation at both collective and individual levels. In applying the notion at the individual level, she details the way young people quietly subverted and resisted local health service processes. However, Stewart's analysis suggests invited and uninvited participation are discrete practices, finding "a reasonably clear distinction between a space in which the 'rules of the game' are defined by organisational actors, and on in which they are improvised by citizens" (Stewart, 2016: 128). Our analysis suggests that this distinction may be less clear, and that there

can be movement between these at the level of individual participation.

Marres' (2012) notion of material participation continues the concern with surfacing the underlying normativities of participation, but focusses on participation located in everyday material practice. In her study of environmental politics, she points to the way that material entities, such as everyday technologies of carbon accounting are "invested with capacities to mediate engagement, and [...] raises analytical awareness of the situated, material, normative and performative aspects of participatory practices" (Nielsen and Langstrup, 2018: 261). Marres brings to light two distinct logics of material participation. On the one hand, she documents devices that are meant to mitigate the environmental costs of everyday life "without problematizing or altering the [everyday] activity itself" (Marres, 2012: 66). This form of participation is meant to require little effort, intended to make things easy for ordinary publics. Marres (2012: 67) argues: "the notion that participation in public affairs must somehow be made 'doable' for everyday people – who lack the time, space and shared knowledge that political engagement requires – has been an important trope of liberal theory". She notes, this has particular normative implications regarding the "bifurcation of two domains of engagement with public affairs – one for professionals and one for laypeople" (Marres, 2012: 68). Yet, she suggests, the trope of making things easy comes undone in evaluations of initiatives. These talk of the "hidden costs" of involvement, which require "more investments, labour and disruptions than promotional narratives...assume" (Marres, 2012: 77). While these evaluations bring into view the limits of the trope of minimization of effort, they do not necessarily problematize this logic, but might be used as a justification for abandoning the policy of participatory approaches to environmental change. Marres identifies an alternative, pragmatist logic of 'the more invested the more engaged' based on her analysis of individual and collective domestic environmental projects which documented the time, effort and disruption, that is, the costs of environmental change. These more experimental engagements with the valuations of environmental action have a performative effect,

helping to raise questions about the broad social distribution of costs. The problem here is not with "people who aren't interested" or with "issues that are too complex" (Marres, 2012: 80), but with rethinking the issue of environmental participation.

In our analysis, we draw on Marres' concept of material participation and the different logics of participation this incorporates to consider the kinds of investments that are imagined, required or offered by self-monitoring and link this to notions of invited and uninvited participation. In the following paragraphs we discuss existing studies of self-monitoring, considering both health sciences and social sciences analyses and relate them to the concepts we have highlighted, whilst also drawing on insights from the sociology of health and illness. We observe that, just as environmental participation is normatively multivalent, scholarship on self-monitoring suggests that there are multiple registers of patient involvement/participation.

Schüll's (2016) analysis of the marketing of tracking technologies resonates with the liberal trope of participation made easy through its focus on 'micronudges' and the move to presenting 'actionable data'. These are pitched "as a way to embrace the project of self-enterprise without undertaking the tedious, nebulous, and anxiety-provoking work of lifestyle management" (Schüll, 2016: 329). In other settings, patient investment in participation is valorised. Danesi et al. (2020) for example illustrate how clinicians hope their patients will invest effort in learning how to use and interpret flash glucose monitoring, seeing it both as a pedagogic tool and an opportunity to start a conversation about insulin. (On this latter point, see also Fiore Gartland and Neff, 2015). Health sciences scholarship also hints at the valorisation of investment in blood pressure self-monitoring, which might facilitate lifestyle change or better 'medication adherence' (Fletcher et al., 2016). Other scholarship (e.g., West et al., 2018), focussed on the utility of patient-generated data, presents a rather ambivalent picture of the investments expected of patients and clinicians. This highlights clinicians' concerns about accuracy and the workload implications of managing this data (RCGP, 2010, 2013; Morgan, 2016; Zhu et al., 2017,

Morrissey et al., 2018; Fisker et al., 2021). It has been suggested that patients receive little feedback or interpretation on the data they generate and that these data are used as a check on patients rather than to facilitate dialogue (Morgan, 2016). This scholarship is suggestive of attenuated patient investments which might approach 'participation made easy': Patients are providers of data with no need to engage with or interpret these data, reinforcing a continued division between professional and lay worlds, in other words a thoroughly liberal form of engagement in Marres' terms.

The foregoing scholarship suggest that patients' self-monitoring is not unequivocally welcomed by clinicians, who express concerns about accuracy, workload, and also about patient anxiety, which forms a recurrent trope in clinical discussions (e.g., British Heart Foundation, 2015; Morrissey et al., 2018; Fiske et al., 2021). These concerns imply that clinicians have doubts about patients' capacities to engage with self-monitoring in the right ways and amounts. We suggest these concerns might be understood as issues of professional authority, which, as medical sociologists have discussed, are inextricably linked with patient participation (e.g., Pilnick and Dingwall, 2011). As this scholarship shows, patients are well aware of the tensions associated with participation; they may be reluctant to discuss their own self-care practices (Stevenson et al., 2003) and tread carefully when trying to insert their own ideas or concerns into medical consultations to avoid usurping the epistemic authority of their clinicians (Bergen and Stivers, 2013; Stevenson et al., 2021). While not explicitly referenced, there are hints of this in scholarship relating to how clinical trials of self-tracking technologies work out in practice. These have shown how patients may curate (Weiner et al., 2020) their records in preparation for sharing them with their health care professionals, leaving out or including particular data, (Nielsen, 2015; Piras and Miele, 2017; Danesi et al., 2018) as a way to keep the clinic at a distance or make their own concerns visible or legible (Street, 2012) to their clinicians. Given the 'interactional delicacy' (Stevenson et al., 2019) of participation at the clinic, these practices of curation may help patients avoid or raise particular issues. They also illustrate the perhaps unexpected investments

patients make when they are invited to self-monitor. To sum up, the scholarship on self-monitoring initiatives suggests expectations of both quite circumscribed and highly invested patient participation that align with Marres' notions of 'participation made easy' and 'the more invested, the more engaged'. It also suggests that patients may make unexpected investments in self-monitoring and we have linked this to the tensions of patient participation. Considering self-monitoring through the lens of **material** participation helps to centre how materials (such as self-monitoring records) might be enrolled in maintaining clinical authority or in negotiating tensions of patient participation, and thus reinforcing or mitigating divisions between professional and lay domains.

The scholarship we have discussed above focuses on how patients respond to invitations to engage in self-tracking initiatives, such as clinical trials or demonstration projects. We aim to build on this scholarship by considering how patients participate and how clinicians respond in practice when participation may or may not be expected. In contrast to the scholarship discussed above, our own study was not part of a specific clinical initiative or trial. We focus on the case of blood pressure self-monitoring undertaken with devices acquired independently of the clinic, and how this self-monitoring is managed in everyday clinical practice. While our participants had all acquired their own devices, we do not think their participation in the clinic should be seen, a priori, as uninvited. In the UK, a range of blood pressure monitoring devices are available to buy in supermarkets, pharmacies and online retailers (see Williams et al., 2020 for more detail) and self-monitoring is supported in clinical guidance as one response to white coat hypertension (NICE, 2019), that is, raised blood pressure induced by visiting the clinic. Furthermore, while our participants had bought (or had been gifted) their own monitors, their accounts suggest that their home monitoring was sometimes enrolled into the clinic, through being commissioned by their doctor or nurse to measure in advance of review appointments. This 'invited participation' is one way that clinics respond to the problem of white coat hypertension. All of this helps to expand ideas around invitations to participate, illustrating that

these may be extended in different places and ways. Commercial offers and clinical guidelines both, arguably, constitute invitations to participate in self-monitoring. Clinicians may extend specific invitations to participate in everyday clinical practice through inviting patients to use their own monitoring devices. Yet, patients may also initiate their own monitoring, uninvited in this context, which, as we will demonstrate, they may hope to discuss with their clinicians.

In this paper we expand on the literature on patient participation in self-monitoring, focussing not on innovations, initiatives or trials, but on everyday practice. We consider the case of blood pressure monitoring as a well-established exemplar of a device that has escaped the clinic and is now widely available as a consumer technology, yet remains of central clinical interest (See Williams et al., 2020). We explore how home blood pressure monitoring re-enters the clinic to consider how patients' self-monitoring is incorporated into clinical care, how self-monitoring materials mediate participation and how we might characterise the participation that is evident within the everyday practices of the clinic. Our analysis draws on and links Marres' (2012) ideas concerning the different participatory logics underpinning material participation and Wynne's (2007) notion of invited and uninvited participation. In doing so, we apply and extend these concepts in a new context.

## **Methods**

This paper draws on data collected as part of a 3-year study of self-monitoring, focussing on the cases of blood pressure (BP) and weight/BMI, with this paper focusing solely on BP monitoring. Ethical approval was given by the lead author's institutional Ethics Review Committee and full details of the overall study design and methods can be found in Weiner et al. (2020), Will et al. (2020) and Andrews et al. (2020). Two distinct data sets are drawn on in this paper. The first data set was collected via interviews with people who self-monitor their blood pressure and the second from focus groups with primary care professionals who talk about their management of patient self-monitoring.

For the interviews, we recruited participants through advertising on email lists at three UK universities and noticeboards across campuses, at older people's groups and at community centres in less-advantaged areas. Participants varied in terms of age, sexuality, ethnicity, socio-economic background and health. We undertook 47 semi-structured interviews involving 55 people, including 8 interviews with couples. Interviews were designed to explore the broad practices of self-monitoring, including the potential wider infrastructure of care involved. Crucial to our study was its focus on people who had acquired or purchased their BP monitors independently of the clinic. Interviews explored how people came to acquire their BP monitors, what they do or do not do with these devices, what records they keep (if any), who else, if anyone, is involved with the practice and with whom data are shared. People came to monitor their blood pressure for many reasons. As might be expected, some of our participants had been diagnosed with hypertension, and had been prescribed medication. Others had experienced a high reading in the clinic or elsewhere. A few related their self-monitoring practice to general fitness and health narratives, family history or saw blood pressure monitoring as a form of stress monitoring (See Weiner et al., 2020). While our inclusion criteria meant that all participants had acquired their devices independently of the clinic, we found that health care professionals often featured in their interviews. Clinicians were in evidence, for example, in narratives about how people started monitoring their BP or how they came to acquire devices, how they keep and with whom they share records, and their understandings of blood pressure.

In the second stage of the research, we undertook focus groups with primary care practitioners, to explore their views and experiences of managing self-monitoring in the clinic. We employed a set of vignettes to structure these focus groups and prompt discussion. We developed these vignettes drawing on our interviews with people who self-monitor, selecting excerpts from these interviews to provide good illustrations of interviewees' talk relating to the clinic (See Andrews et al., 2020, for further discussion of vignette methodology and detail



of procedure). We recruited general practitioners (GPs) and practice nurses (PNs), through two NIHR Clinical Research Network (CRN) clusters<sup>1</sup>, aiming for diversity in the participating practices. In total, we conducted five focus groups, with a total of 21 health care professionals. Three of these focus groups involved health care professionals based in lower socio-economic areas, and two involved health care professionals based in higher socio-economic areas.

Interviews and focus groups were audio recorded, transcribed in full and analysed thematically (Hammersley and Atkinson, 1995). We collaboratively developed a coding frame for the interviews, which was broadly informed by our theoretical interest in everyday practices and care infrastructures, whilst also allowing space for emergent themes. For the focus groups, we devised a set of codes where some themes aligned with the topics of the vignettes, which were themselves informed by the themes from the interviews, and others were more emergent.

In the analysis below, we consider how the clinic and clinicians feature in interviewees' talk about their self-monitoring, and how clinicians propose they respond to their patients' self-monitoring practices. We focus, for example, on reports of self-monitoring being discussed in clinical consultations or of people submitting their own records to the practice (e.g., "drop them off at reception"). We pay attention to moments when participation appears to be invited or uninvited and movements between these, to the underlying logics of participation that emerge, and to the ways in which materials appear to mediate these different enactments of participation. The analysis is divided into four sections. The first two draw on both interview and focus group data to consider the different ways these suggest patient participation in self-monitoring is enacted in the clinic. The first section illustrates the way patients might be invited to self-monitor in relatively circumscribed ways which we suggest equates with participation made easy. We then consider occasions where participation appears at first sight to be uninvited, and the more involved and invested participation that appears to be associated with this. Then, drawing solely on the focus group data, we detail clinicians' concerns about investments

in self-monitoring, both the investments they need to make to manage this in the clinic, and the potentially burdensome (over)investments of their patients. The final section suggests that clinicians sometimes manage or respond to this by retreating to 'participation made easy'.

## Analysis

### ***Invited participation as participation made easy***

Interviewees were recruited into our study on the basis that they had bought their own monitors. Just three explicitly told us that their doctor had suggested that they buy a monitor, a clear clinical invitation to participate in blood pressure monitoring. Yet the clinic loomed large in many other interviewees' accounts of their monitoring practice and clinicians sometimes appeared to extend invitations to self-monitor blood pressure and support this. In this section we will suggest that such invitations involved an expectation of relatively limited and circumscribed patient investments that conform to the logic of 'participation made easy'.

Interviewees told us that they drop off (i.e. deliver) their own records, or bring them to clinic appointments, sometimes in response to a request or invitation from their clinicians. Geraldine, a woman in her late 70s, tells us she has white coat hypertension and was asked to take her blood pressure for one week in the run up to her appointments. She tells us her readings are used as the basis for treatment decisions "whether I get tablets for six months or he says I'd like to see you again in three". Interviewees' accounts of these appointments indicated something of the investments in formal care required or expected of patients. For example, they expressed a great deal of uncertainty about what happens to the self-generated data that they give to their clinicians. Interviewees often suggested that their self-generated records were "scanned-in" or "put on my notes". However, the degree to which this data became part of their formal electronic record was not clear.

Henry (aged 65) provides home monitoring readings as part of the process of requesting a repeat prescription. He compiles his own hand-

written readings, completing one sheet per day and taking readings over several days. He says he has dropped these sheets off with the receptionist in the past, although the last time he scanned in the sheets and emailed them to the practice. We asked if his doctor saw these sheets, and he responded:

Well, I don't know if he sees the detail. He sees the average. Whether his receptionist calculates an average and just puts that on my record or whether he sees all the details, I don't know. I don't know if you've seen a GP lately but when you see a GP he's just looking at a computer screen and you don't really know what he's got on it.

Henry's account neatly illustrates the way, from the patients' perspective, the process of capturing and processing home monitoring data in the clinic may be completely black-boxed. What happens to the data and the sense in which it is useful for the clinic, and ultimately, potentially, also for the patient, remains opaque. In these circumstances, however, interviewees did sometimes formulate hunches about the utility of their data. Nora (aged 33), for example, recounts that she hands in her readings to the reception, and although she had not heard anything directly, her repeat prescription was approved. She surmised that "somebody somewhere looked at it, decided not to increase my medication and approved my next one [prescription]".

Other interviewees conveyed more ambivalence about how and whether their own readings were useful to the clinic. Emily, a woman in her 30s, has hypertension and takes medication. She tells us that her doctor recommended she bought a blood pressure monitor and that she had used it particularly around the times of settling into her medication and medication changes. While her doctor had apparently asked her to monitor during these times, she is uncertain what use he makes of her readings, which she collates in a diary to take to appointments. We asked if her doctor looked at the readings and she responded:

Emily: Yes, he would have looked at them. [...] He'd never note them down anywhere though.

Interviewer: Yes. Do you remember him saying anything about them?

Emily: He probably would have gone, umm, and made a very concerned face, because he seems to be that type of person [...] He just looked at them to see if they were kind of where he wanted them to be or not.

In the focus groups with clinicians, we drew on the excerpt above from our interview with Emily and asked clinicians about how they might work with their patients' self-generated data. They suggested they would, and do, use patient-generated data as the basis for prescribing decisions and do record self-generated data in patients' electronic records, both in a designated numeric field and in narrative fields. They suggested a variety of ways they might manage their patients' data including writing two or three of the home readings into their notes, selecting the "best looking reading", calculating an average, writing down a range, or getting a feel for the data, as one GP explained "I look and think that looks about right. You can get a ballpark average in your head". However, the use the clinicians make of patient-generated data may not be visible to patients as it may take place outside of the consultation, as suggested by one of the GPs:

GP1(2): [I'm] pretty confident the doctor is, kind of, looking at them [Emily's records] and she says he's not writing them down, but I wouldn't usually write anything down during a consultation. I would write it down afterwards and obviously you're looking for thresholds and so if the blood pressure was obviously well controlled [...] if every reading is below 140 over 90, then I think the exact number is maybe not directly relevant [...] So I'm, sort of, reading between the lines, but thinking the doctor has looked, he's probably happy with what he's seen. She's obviously ambivalent, she's not sure whether or not the doctor is taking it seriously or really cares. I hope my patients don't think that. I think I tell them the conclusion I've drawn from what they've brought.

The doctor's equivocation at the end of this excerpt seems a quite potent indication of the investments expected of patients, where clinicians' investments in their patients' self-generated data may remain unknown and clinicians may, at most, communicate an outcome. Clinicians' support of self-monitoring figured around

the time-limited and structured practices of producing the right amounts and right kinds of readings to support scheduled review meetings and clinic routines e.g., an average of three consecutive readings taken morning and afternoon over a period of one or two weeks. This was seen as an efficient way for clinicians to identify issues and make medication decisions. A clear sense of this was presented by one of the clinicians (GP1(4)) who explained they often asked people to drop results at reception, and only invited these patients for an appointment if the doctor identifies an issue. He explained:

In general, we're trying to get away from checking blood pressures ourselves and just really dealing with the data and seeing a person if they've seen a healthcare assistant and their blood pressure has been up or their home blood pressure has been up, bringing them in to talk about what we do about that [...] I think we're trying to get away from GPs doing that [checking blood pressure] and so the GPs have got the time to see the people that need changes and discussion.

In the data we have discussed so far, patient participation emerges as an expectation that patients drop off their readings and wait for either a repeat prescription or to be called into the clinic. These accounts of preferred clinic practices and what happens to patient-generated data may be thought of as enactments of 'invited participation' that depend on very clear divisions of labour. Patients are expected to produce and provide readings but are not expected to invest in understanding or interpreting these readings or their implications for treatment decisions, which appear to remain largely the clinicians' responsibilities. This seems to enact the liberal logic of 'participation made easy'. Our argument builds on Marres (2012: 68) idea that within this logic, participation is made doable for ordinary people whilst retaining a separation between professional and lay "domains of engagement with public affairs". In this case, we suggest, participation is made doable for **both clinicians and patients** whilst maintaining a division between patient and professional domains of engagement with health care.

### ***Uninvited participation as more invested and more engaged***

Patients may be glad if their home monitoring reduces the number of appointments they have to attend, or it provides a smooth process of requesting a repeat prescription. Yet the clinic routines are premised on clinicians' understanding of the purpose of self-monitoring, as broadly a way to identify patients whose blood pressure is poorly managed ("up") in order to discuss medication strategies. This does not recognise that patients may have their own reasons for wanting to talk with their clinicians. Our interviews suggest that people may sometimes take matters into their own hands in unexpected or (at least initially) uninvited ways, using monitoring to prompt a discussion in the clinic to raise their own concerns. These include, for example, that they do not want, or think they do not need, to take medication, that they have white coat hypertension and would like to avoid further (in their view) unnecessary trips to the clinic, that they are worried about their blood pressure, or they would like a change of medication. In this section we will suggest that accounts that appear to involve uninvited participation entailed enactments of an alternative logic of participation which is more invested and more engaged than 'participation made easy'.

A number of our interviewees talked of their wish to come off or reduce their medications, in keeping with broader lay 'resistance' to pharmaceuticals (Pound et al., 2005; Weiner and Will, 2016). Bob and Alice are an older couple who both have hypertension and other chronic conditions. Their daughter originally gave them a blood pressure monitor, and during the interview a clear story emerged of them both using their own self-monitoring records to negotiate reductions in medication. Bob's story shows his deliberations about wanting to reduce his medication and the way this was entwined with his desire to be a good citizen, not waste state resources, be a good patient and maintain his relationship with his doctor. The chronology of events is not clear in Bob's narrative. We could not untangle when he started taking his records to the clinic or whether this was in response to an invitation from the clinic to do so. It is nevertheless clear that, at some point, the clinic has advised him how to self-monitor ("the



nurse told me to do it three times”) and requested that he bring in his device for calibration, in Alice’s words, “to make sure it was working right”. The boundary between invited and uninvited participation in BP monitoring is unclear here with the clinic clearly supporting, and thereby, arguably, ‘inviting’ a practice that it had not necessarily initiated. However, Bob’s account of how he used the data from his BP monitoring to justify a reduction in his medication offers insights into a trickier set of negotiations about the boundaries of invited and uninvited participation. Bob described how he had slowly and incrementally reduced his medication, whilst keeping a check on his blood pressure, and how he eventually came to “confess” this to his doctor:

Bob: The reason why I went is because I were being prescribed these tablets, so I were basically throwing the tablets away [...]  
 Alice: They were on repeat prescription, you see. I said, ‘why don’t you just stop accepting them?’ He says, ‘but then they’ll know I’m not taking them’.  
 Bob: So initially, I were a bit frightened to tell him, because I were accepting tablets and not taking them, and I thought, God, I shouldn’t be doing that. And then, I thought I’ve got to go and tell him. So I made my mind up to confess, so to speak. It’s like *Crimewatch*<sup>2</sup>, isn’t it? So I went and I says, listen [...] I’ve reduced it and reduced it, and I’m now taking ten milligrams, I’ve been taking them for a year or so, whatever, and these are my readings [...] So they agreed that, they said, yeah, well, stop taking them. But if I hadn’t have done my own experiment, I’d have still been taking 30 milligrams.

According to Bob’s account, his doctor had explicitly told him not to reduce his medication. Bob then took matters into his own hands, through his “own experiment”, but the account conveys the delicacy of raising these kinds of issues in the clinic. His account can be recognised as a classic example of a patient disclosure of a medical misdeed (Bergen and Stivers, 2013), that is, Bob’s admission of his failure to follow his doctor’s recommendations. Such disclosures have to be managed carefully as they challenge doctors’ authority and risk exposing patients as having acted improperly. We hear this in Bob’s use of the phrase *confess* and in his account of using his blood pressure readings (*and here are my readings*) to demonstrate that his

action was medically warranted. In the end, Bob’s initially uninvited participation in his own medication management appears to have been accepted and to have brought about a satisfactory outcome, that is, a reduction in pills with his doctor’s knowledge and sanction. The account illustrates clearly how the materials of participation act as a highly significant part of such enactments, with the blood pressure records being mobilised explicitly to facilitate this more engaged form of participation.

In other instances of what appeared to be uninvited participation, people wished to intervene in the diagnostic process rather than medication management. Interviewees were concerned to substantiate they have white coat hypertension, that is, high blood pressure induced by having readings taken in the clinic, which meant that they might not require (further) clinical intervention. Some interviewees reported taking their own readings to the clinic as a foil for the readings that were taken by clinicians in the clinic. Here, interviewees might want to fend off further appointment invitations. Brenda, a retired nurse in her early 80s does not expect her readings to replace the clinic taking her blood pressure or for her own readings to be entered into her record. She takes them as a way to bargain against repeat visits:

Interviewer: did you take the readings with you to the surgery<sup>3</sup>?  
 Brenda: I have done but they always take their own, they have to. And I think, possibly, when I started showing them this, they didn’t ask me to keep coming back...I used to take a whole page of data at a time.  
 Interviewer: Right but did you think they wrote it down or do you think they just recognised  
 Brenda: No they just  
 Interviewer: They acknowledged it?  
 Brenda: Yes  
 Interviewer: Oh okay that’s interesting, so it’s a kind of bargaining chip in some ways?  
 Brenda: Yes and we said why do I have to come, look, you know?

In this account, Brenda offers her own readings as a way to evidence or corroborate that she has white coat hypertension, to support her request

to not have to keep returning to the clinic. As in Bob's account, Brenda also suggests a need to tread carefully when negotiating an apparently uninvited aspect of BP self-monitoring. As a retired nurse, it is possible that the clinic might see Brenda's own readings as credible, but she is modest in her expectations. She evokes her understanding of clinic workings (*they always take their own, they have to*), providing a tacit acknowledgement of the boundaries of clinical responsibilities. As in Bob's account, the mobilisation of the materials of participation (here, *a whole page of data*) appears central to warranting Brenda's uninvited participation in her blood pressure management.

Bob and Brenda's accounts demonstrate different investments in participation than those scripted by clinicians' versions of invited participation (*drop off your data and wait for a response from the practice*). These might be seen as attempts to change the frame of participation, reimagining what are salient (Wynne, 2007) issues for clinical consultations, to make space for patients' concerns that do not necessarily align with those of clinicians. These investments are not meant to replace or necessarily challenge clinical care, but to bring patients' concerns into the clinic in such a way that they are made legible (Street, 2012) to clinicians. Yet, the delicacy with which such investments are approached indicates that interviewees are aware of the potential threats these pose to clinical authority and the asymmetry of clinical relationships (Pilnick and Dingwall, 2011). Through observing this delicacy, the investments become recognisable as enactments of uninvited participation, at least initially. We have noted the way interviewees drew on materials in these enactments to help warrant their actions. In the following section, we focus on clinicians' accounts of their response to high levels of patient investments in self-monitoring. We will suggest that this is largely interpreted as problematic and appears to elicit invitations to engage in ways that transform investments to conform to 'participation made easy'. We continue to pay attention to the role of materials in these moves.

### **Troublesome/troubling investments.**

Patient participation, whether invited or uninvited, was often viewed as troublesome for clini-

cians who expressed concern about the levels of investments or effort required of both themselves and their patients. Dealing with patients' own data was experienced as time consuming, especially when people provided large numbers of readings, or when records were not structured in the preferred way. A discussion between two GPs [GP1(4) and GP2(4)] provided a particularly rich illustration of the difficulties clinicians face and the pragmatic ways they manage patients' data within the time constraints of primary care practice. One suggested "Some people just bring, like, it'll be a storm of numbers that they throw at you and expect you to [manage them]". He explained that this was one reason they have a proforma to give to people to structure the data returned to them and that there was "a big box at the bottom that says average". In this way, the practice encourages people to calculate the average themselves, because for clinicians "it's time consuming" and "if you've only got ten minutes, you can't spend five minutes putting numbers into a calculator to work out an average". His colleague described "when people bring in a big sheet that's not on the proforma, that is a real heart sink moment". They went on to explain how they work with the data, suggesting they will record an average in their notes, and have the raw data scanned into the record. When there is "a massive pile of data" which are "safe" [ie within target range] then they might record a range or "take a guesstimate average" rather than calculate an average.

As mentioned above, some practices provided a structured proforma as one way of investing in helping their patients to produce useful or credible data. Clinicians appeared to have ways of assessing the credibility of the patient generated records they receive as the following comment suggests:

I get a lot of hand-written things dropped in, whether I was expecting it or not and I think [...] if the data looks useful and credible, you know, so there's a column that says morning and a column that says afternoon and they've carefully written it down for a week and that was on the advice of a clinician, then I think that will certainly be good enough for me (GP1(2)).

Here, credibility is judged through the correct structuring and completeness of the data. It is also judged, in part, on the basis that self-monitoring had been licensed by a clinical colleague. The distinction between invited and uninvited participation is explicit in this quote (*whether I was expecting it or not*) and invited participation is privileged (*on the advice of a clinician*) in as much as this is likely to be seen as more credible. We also see that participation may be invited in specific ways involving engagements with clinic-sanctioned materials (here, a structured proforma) that mediates participation.

Clinicians framed self-monitoring as potentially burdensome for their patients in a number of ways and expressed a wish to protect them from the responsibility and potential time, cost or anxiety associated with this. One clinician (GP1(3)) commented on the time “burden” of self-monitoring: “People have got better things to do with their lives, than checking their blood pressure all the time”, suggesting that the more anxious people were about their readings the more time-consuming monitoring becomes. Another GP (GP2(4)) commented “if their blood pressure is okay, I tell them to put your machine away”. Clinicians were also sanguine about the utility and significance of blood pressure monitoring, recognising the rough accuracy of both home and clinic readings and expressing a toleration of variations. They viewed high blood pressure as something that does not require an urgent response, but as something to be sorted out “over months and years”. Educating patients on these matters was seen as a further way to allay anxiety and protect them from the burdens of monitoring. As one clinician commented (GP1(2)): “Our aim is that they understand that blood pressure is important, and this healthy balance with it, that it’s really just not a massive deal, especially when we know it’s well controlled and we just need to check it once a year and everything will be fine and let’s just all chill out”.

During the focus groups there was just one comment that stood out as counter to this narrative of troublesome or over-investments. In this instance a nurse recognised the demands on patients of self-monitoring but did not frame this as inappropriate. Responding to our vignette that showed Emily’s ambivalence about the value of her self-

monitoring data (discussed in the first section of the analysis), this nurse responded by suggesting that patients needed encouragement. It is very notable however, that she draws on the case of diabetes rather than blood pressure monitoring in her own example:

PN2(1): sometimes if people come and bring their glucometers and show their readings. I’ve got an HB1 [reading<sup>4</sup>] and I think that’s more interesting to me than some of these readings and I don’t value the work and the time they have put into producing this information and bringing it to me, and then I feel bad. But, you know, it’s usually to do with time and things. But I think it’s incredibly important that we do value, you know, we’re asking them to do quite time-consuming stuff. And then if we don’t show that we’re actually valuing what they’re bringing us, that’s really not very good, and it’s not going to encourage them to carry on doing it, I guess.

In this case, rather than minimising investments (*put your machine away, chill out*), the *time-consuming work* of patients’ ongoing investments in self-monitoring is to be supported and encouraged. It is possible that the nurse is referring to the pedagogic value of self-monitoring as, in clinical terms, she does not value patients’ glucose measurements as highly as her own HB1 measures. It was notable that a pedagogic narrative about blood pressure self-monitoring did not feature in our focus groups, although we discerned this as a possibility within the clinical literature (e.g., Fletcher et al., 2016).

With the exception of the last quote, clinicians’ comments suggest they are concerned about the potential over-investment of their patients in self-monitoring and clinical care. These are potentially seen as calling for too much effort from both patients and clinicians. As embedded in calls to *put your machine away, check it once a year* and *just chill out*, clinicians’ comments again seem to imply a logic of ‘participation made easy’. The discussion also illustrates how clinics may draw on materials (such as the proforma) to try to contain patient investments to make them manageable for both patient and clinician. In the final section we will address instances where clinicians discussed responding to what they saw as inappropriate

patient investments that are troublesome for both patients and themselves. The accounts suggest that they may respond with an invitation to participate in ways that clearly reinstates the logic of 'participation made easy'.

### ***The retreat to 'participation made easy'***

As we have discussed in the previous section, dealing with large volumes of patient-provided data was difficult for clinicians to manage. The following excerpt suggests it was also seen as possibly indicative of inappropriate investments by patients, associated with anxiety:

So I got one today which was probably put in the eight page letter, 50 blood pressure readings, unspecified time [...] Timewise it's impossible to take an average of that many blood pressure readings. [...] there's the thing you're interested, yes, done properly, yes. Done improperly, i.e. infrequently, at the wrong time, associated with lots of anxiety. It's not that you're not interested, but it's not helpful [...] So I sent a message to reception saying, thanks for your blood pressure readings, I can see you're worried about them, what I would suggest you do is do them twice a day for a week and book an appointment with me [...] and we'd use the average of those recordings to make our treatment decisions. (GP1(2))

We do not know the patient's rationale for dropping off these data, whether the clinician was familiar with the patient or was inferring that the volume of data relates to patient anxiety. It is possible that the patient was worried, but we can suggest potential alternative rationales such as trying to look credible (more data shows commitment) or trying to have concerns recognised. The clinician's response, requesting that the patient repeats the measures and book an appointment, shows how the doctor tried to contain the patient's investment to focus on the "the thing you're interested in" which is narrowed to the doctor making "treatment decisions". The patient is therefore offered an attenuated role limiting their potential to bring their own concerns to the consultation. This example suggests how ostensibly uninvited participation may be transformed into an invitation to participate in ways that facilitate clinical practice which, at the same time, reinstate a logic of 'par-

ticipation made easy'. We suggest this retreat to 'participation made easy' make participation easy or doable not just for patients but also for clinicians. From the clinicians' perspective, particular forms of participation facilitate clear treatment decision-making within the time constraints of primary care consultations.

In another example, it was interesting that a practice nurse (PN1(2)), responding to a vignette which she interpreted as representing an anxious patient, suggested that offering 24-hour ambulatory monitoring "takes the pressure off" people having to do it themselves:

It's on for 24 hours and then you can forget about it, he's not got the added anxiety of, oh, I've got to take my blood pressure and, oh, what's it going to be and am I doing it right? And all that, am I writing it down properly? And what does it actually mean? He can wear it, forget about it for 24 hours and then it comes back to us and then we can look at it and reassure him that, actually, those 24 hours' worth of readings were fine.

Twenty-four hour ambulatory monitoring involves clinical staff emplacing a wearable monitor on patients. The automated device takes and records readings at regular intervals without the intervention of the patient, whose involvement is limited to returning the device to the practice. Thus, the nurse is suggesting a minimisation of patient investments, mediated through a material intervention (the use of a 24-hour ambulatory device). Resonating with Marres (2012), clinicians may recognise the hidden costs of patient involvement, that is, the investments and disruptions involved. Yet, as Marres (2012) suggests, in this instance, rather than troubling the logic, this nurse suggests a stauncher retreat to 'participation made easy'.

Here and in the previous section we have shown how clinicians may view participation as both burdensome for themselves and their patients. Our analysis has also suggested that clinicians may privilege invited participation and find ways to transform uninvited into invited participation in a way to make it less burdensome for both patient and clinician, and in doing so effect a retreat to the logic of participation made easy. Through their discussions, clinicians

displayed concern for their patients' wellbeing, and a desire to protect them from unnecessary burdens and from anxiety. On the one hand, this can be read as an expression of their care for their patients. Yet, in their desire to protect patients from the burdens of monitoring beyond that sanctioned clinically, or even in suggesting to take home monitoring out of their patients' control through offering 24-hour ambulatory monitoring, these discussions fail to recognise the rationales or projects of some patients' own monitoring regimes. Through their investments in self-monitoring, patients may want to communicate one of a number of different concerns (such as a wish to reduce medication or avoid further clinic appointments), implicitly opening up the saliency of different issues within clinical consultations. However, in framing these concerns as patient anxiety or unnecessary burden for patients, clinicians risk closing down the alternative rationales embedded in their patients' investments.

## Discussion

In setting out their agenda for remaking participation in science and democracy, Chilvers and Kearnes (2020: 358) note the recent turn from studies of discrete participatory events to scholarship that attends to the diversity of participation, addressing "the increasing multiplicity and multivalence of public engagement with(in) contemporary technoscience and democracy". The current study contributes to this agenda, employing, linking and building on the ideas of invited and uninvited participation (Wynne, 2007), and material participation (Marres, 2012) in health care.

We contend that the existence of a consumer market for self-monitoring devices and an increasing call for self-monitoring within health policy both offer more or less explicit invitations for people to participate in their own health care. In our analysis we have considered what this participation looks like when it enters the clinic, treating participation as a dynamic sociomaterial practice which may emerge in different ways. Our analysis has explored the relationship between invited and uninvited participation and their links with the underlying logics of material participation in various aspects of BP self-monitoring. We

have argued that when clinicians imagine or invite participation, this aligns with a logic of 'participation made easy', whereas the uninvited participation our interviewees discussed aligned with a logic of 'the more invested, the more engaged' in participation. We make two further moves in our analysis. First, by applying Marres' (2012) ideas in a new context, everyday clinical practice, we extend the logic of 'participation made easy', suggesting this might apply to professionals, here clinicians, as well as lay people. Second, while we identified invited and uninvited participation in BP self-monitoring, we do not see these as distinct and immutable, but observed movement between these. In the following paragraphs we will outline these arguments in more detail.

Clinicians may invite patients to self-monitor their blood pressure to service review appointments, for the smooth running of clinical interactions and the clinic. Clinicians' accounts suggested that they might invite their patients to self-monitor and make records in circumscribed ways over particular time-frames (e.g., record twice a day for a week) and that these data will be used to make prescribing decisions. We have proposed that this enacts an implicit logic of 'participation made easy' (Marres, 2012) which involves a division of labour encoding a traditional division of expertise. It is the patients' job to produce (sometimes prespecified kinds of) data, and the clinicians' job to interpret this and infer treatment plans. While this might be interpreted as paternalistic, we suggest that from the clinicians' perspective, participation made easy is understood as participation made useful or useable in the context of the clinic. From this perspective, treatment decisions can be made within the time constraints of primary care work, without causing undue stress, worry or work for patients. We note that through these enactments, patient participation is made easy for both patients **and** clinicians, containing the investments required of both. Yet, we have suggested, through these enactments, some patient concerns get lost.

We have also demonstrated occasions when patients' participation is uninvited in the context of the clinic, when people use their self-monitoring as a way to raise their own concerns here. In the examples we discuss, we saw unsolicited



participation in self-monitoring linked with a wish to reduce medication (and in that case also unsolicited participation in medication management) and with a wish to substantiate white coat hypertension and therefore reduce the requirement for further clinic appointments. This enacts a different, more invested and more involved form of participation centred on the life world experiences and concerns of patients. The analysis illustrated the sensitivities of inserting or making these concerns legible (Street, 2012) to clinicians, as these are implicitly understood by patients as a potential threat to clinical authority. We can interpret this through the language of Wynne (2007) and Marres (2012) to suggest that the delicacy with which this is approached helps to make visible the normativities of different enactments of participation.

We have demonstrated that clinicians expressed a great deal of concern about the investments or efforts required of both themselves and their patients when patients participate. These were expressed as judgements about the credibility of patient-generated data, doubts about the proportionality of patients' investments relative to the issue at hand, and the time investments required of both clinicians and patients. We have shown how instances of uninvited participation might be subverted when clinicians respond by inviting their patients to participate in circumscribed ways, and thus revert back to a logic of 'participation made easy'.

We know of only one other study (Stewart, 2016) that draws on the idea of uninvited participation in everyday individual clinical interaction. Our findings resonate with Stewart's (2016) in the sense that her data also highlights the sensitivity of uninvited participation – her young participants quietly subverted service use while avoiding direct challenge of clinicians. Yet, Stewart (2016: 128) implies a clear division between invited and uninvited participation, suggesting a clear distinction between the spaces in which these take place. By contrast, in our research we find both invited and uninvited participation in a single interactional space – the clinic – and movements between these. To account for these differences, we might draw on the context of the studies. Stewart's research focussed on uninvited participation where young people engaged in

occasional, transactional service use. In our study, participants had more durable relationships with the clinic and participation emerges as invited or uninvited through specific, but ongoing interactions and negotiations between clinicians and patients.

Our analysis also illustrates the way materials are mobilised to facilitate different modes of participation. As we have discussed, participants' accounts suggest they approach uninvited participation with some trepidation as to the sensitivities of raising one's own concerns in the clinic. Participants described bringing their own records of self-monitoring to clinical consultations which were used to warrant their actions or claims. We have also noted how clinicians might offer structured proformas, provide instructions as to how to self-monitor and record, or offer a device for 24-hour ambulatory monitoring as an alternative to self-monitoring. All of these might work to circumscribe their patients' participation and are offered as part of an invitation to 'participation made easy'.

What broader points might be taken from this analysis? The 'participatory turn' (Prainsack, 2017) in health care is promoted across multiple domains – health care policy, research, practice and industry (Nielsen and Langstrup, 2018). Yet, drilling down with our specific case study, we find not all participation is straightforward or welcome. A broader question emerges, then, about the circumstances and ways in which participation is valorised. Studies by Zhu et al. (2017) and Fiske et al. (2020) suggest that participation through 'digital self-care' (Fiske et al., 2020) is valorised by clinicians only when invited by themselves and/or undertaken with their guidance. Working with the concepts of invited and uninvited participation, we have shown that, in the case of blood pressure monitoring, clinicians tended only to support participation when undertaken at the invitation of, and in collaboration with, themselves, sometimes re-framing what started as uninvited participation in ways that transform it into a clinical invitation.

A second distinction in our analysis relates to the underlying logic of participation. In the case of blood pressure monitoring, we have suggested that instances of uninvited participation sometimes enacted a strongly invested

and involved form of participation whereas the primary care clinicians in our study tended to invoke and revert to the logic of participation made easy. While it is possible there may be circumstances under which greater patient investments in blood pressure monitoring are valorised, this did not emerge in our study. However, the work of Danesi et al. (2020) suggests that in the case of diabetes, more invested and engaged forms of material participation are encouraged, an observation also hinted at in the current study. This is likely to relate to the treatment regimens for these differing conditions since diabetes patients are encouraged to make continuous adjustments to their insulin doses, whereas clinicians tend to adjust regimens for blood pressure medication infrequently (although, as we have seen, patients may take matters into their own hands). It would be interesting to work through what kinds of participation are valorised for other conditions and in other clinical settings.

Finally, we have shown how what we might think of as 'materials of participation' are mobilised in clinical interactions. We have seen how our participants brought materials into the clinic in the hope of making their concerns legible (Street, 2012), but also the delicacy with which this is approached because of the risks of being seen as challenging clinical authority. Other scholars have also attended to the materiality of participation, showing how people may curate the self-monitoring records they share with their

clinicians (Nielsen, 2015; Piras and Miele, 2017; Danesi et al., 2018; Weiner et al., 2020) to either facilitate or avoid particular conversations. This curatorial work is often invisible to clinicians and provides another avenue for patients to pursue their own concerns without directly challenging the authority of their clinicians.

## Conclusion

We have provided a detailed analysis of participation in blood pressure self-monitoring, expanding on different types of participation in the clinic, and showing how this is shaped by the relational and material aspects of clinical care. We have raised some questions about how this might apply beyond the specific case of blood pressure monitoring. Despite policy and industry enthusiasm, we wonder what scope there is for different logics of material participation to be enacted in the clinic, given the unrelenting pressure on primary care, and the intransigent asymmetry of clinical interactions.

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## Notes

- 1 National Institute for Health Research (NIHR) Clinical Research Network (CRN) clusters are local groups of research-active GP practices.
- 2 Crimewatch is a British television programme that reconstructs unsolved crimes to seek information from the public.
- 3 In Britain, people refer to the doctor's office as the 'GP surgery' or 'surgery'
- 4 HbA1c is a measure of blood glucose.