Patient involvement in the design of a novel shared decision-making simulator

Mr Simon Jacklin [1], MPharm MRPharmS, PhD candidate

Prof Stephen Chapman [1], BPharm PhD FRPharmS, Deputy Head of School / Professor of Prescribing Studies and Head of Medicines Optimisation

Prof Neal Maskrey [1], MBChB MSc FRCGP, Visiting Professor of Evidence Based Medicine

[1] Keele University School of Pharmacy, Hornbeam Building, Keele University, Keele, Staffordshire, ST55BG, UK

Corresponding author; Simon Jacklin, s.jacklin@keele.ac.uk, 07597935501 (phone)

Postgraduate Center 0.24, Hornbeam Building, Keele University, Keele, Staffordshire, UK, ST55BG
Abstract

Background: Shared decision making involves the formation of a collaborative partnership between the patient and clinician, combining both of their expertise in order to benefit decision making. In order for clinicians to be able to carry out this skilled task, they require practice. Virtual reality, in the form of a virtual patient could offer a potential method of facilitating this.

Objective: The objective of this work was to create a virtual patient that simulated a primary care consultation, affording the opportunity to practice shared decision making. A second aim was to involve patients in the design of a virtual patient simulation and report the process of the design.

Method: A multi-step design process drawing on patient and expert involvement.

Results: A virtual patient, following a narrative style has been built which allows a user to practice and receive feedback; both clinical and communication skills are required for the simulation. The patient group provided multiple insights which the academic team had overlooked. They pertained mostly to issues concerning the patient experience.

Conclusions: It is possible to design a virtual patient that allows a learner to practice their ability to conduct shared decision making. Patient input into the design of virtual patient simulations can be a worthwhile activity.

Keywords
Virtual patient; virtual reality; education; communication; decision making

Introduction

Shared decision making involves the formation of a collaborative partnership between the patient and clinician, combining both of their expertise in order to benefit decision making [1]. The clinician knows about clinical guidelines, basic science, their previous experiences and case histories. The patient understands their experience of the disease, their lifestyle, what they prefer and expect as well as the risks they will tolerate [2]. Through communication, these two worlds can be combined to benefit the decision-making process [3]. The partnership is not necessarily equal at all times; it does not have to be an exact 50-50 contribution. Patients sit on a continuum, all holding disparate preferences for involvement in their care [4], but all these variants can be considered as shared if the dynamic between the patient and clinician is congruent; a patient may not want to make any final decision, but they should still be involved in the process, eliciting their concerns and views [5]. Shared decision making has been referred to more recently as diagnosing the patient’s preferences to ensure diagnostic, prognostic and treatment plans align with them [6].

The push to encourage clinicians to practice SDM has ethical, legal and clinical dimensions with respect to a patient’s autonomy and their right to choose. The case of Montgomery v Lanarkshire Health Board highlighted that patients need to be involved in their own care, in particular that they should have a say in their own treatment [7]; merely doing what professional’s think is in the patient’s best interest is not sufficient, the process of decision making has to be shared and the patient’s own preferences established. SDM with patients who were initiating treatment for inflammatory bowel disease was shown to increase patient satisfaction, the likelihood of adherence to therapy, and a reduction in costs [8]. Reduction in prescribing [9], increased patient satisfaction [10] and greater patient confidence in decisions made [11, 12] have all been reported.
There are numerous barriers and difficulties inherent in influencing clinicians to utilise SDM more often and to the highest standard [13]. SDM is a skill and a potentially overlooked element is the fact that it requires training and development [14]. It could be easy for healthcare professionals to assume that by carrying out consultations in clinical practice, that they are honing their abilities. This may not be the case as a key factor in the acquisition and development of skills is not just practice but feedback [15, 16]. Routine clinical practice does not often allow the time for self-reflection or feedback from a senior or peer and so by itself is insufficient, compounded by the fact that clinicians themselves are not adept at identifying their own weaknesses [17].

So how can a clinician practice and receive this vital feedback? Current approaches have limitations; simulated patients are not standardised or accessible at all times; video tape is not greatly interactive, neither are lectures or seminars [18, 19]. Ideally what is required is a standardised, autonomous, readily accessible, tailored, low risk and interactive method for practice and feedback. Advancements in technology mean that virtual reality can meet all of these criteria and offer a potential solution; specifically, virtual patients.

Virtual patients have been defined as a ‘specific type of computer program that simulates real-life clinical scenarios; learners emulate the roles of health care providers to obtain a history, conduct a physical exam, and make diagnostic and therapeutic decisions’ [20]. They are standardised, safe, controlled, authentic, can be tailored to a specific clinical situation, permit repeated practice and offer new economies of scale.

The examples of virtual patients in the literature are a heterogeneous collection of technologies, perhaps due to different pedagogical aims. One significant differentiating factor is the type of skill they attempt to develop, technical or emotional. Technical skills encompass managing acute medical emergencies [21], clinical reasoning [22, 23] or triaging patients [24]. More recently there have been attempts to combine the technical skills with the emotional ones in shared decision making [25]; this example is somewhat different from others as it involves both patients and practitioners using the simulation.

Many virtual cases that try to develop emotional skills end up reducing this to a technical exercise; the selection of a single question (e.g. Do you have any medical conditions?) liberates complete, sterilised answers from the patient. Conversation is not like this; there are interjections, misunderstandings and clarifications. Patients are not databases, we do not ask a question which yields the complete answer; we have to form a working relationship and rapport to encourage the patient to disclose both open and hidden agendas [26]. As well as simplification of emotional skills, many virtual patients encourage the application of a treatment plan to a patient, not a discussion about the patient’s values and preferences to arrive at a decision the patient and clinician are content with. Rote use of guidelines has previously been raised as a misapprehension of EBM principles [27] and there are concerns that healthcare is becoming more data driven, neglecting each individual patient and their wishes [28, 29]. Developments in virtual training for consultation skills need to address these concerns.

Patient and Public Involvement (PPI) is the activity of including patients and/or the public in research as collaborators, not participants [30]; PPI is fast becoming a key feature of health research [31]. Efforts have also been made to engage patients and laypeople in medical education, as simulated patients, tutors or advisors on curricula [32]. To our knowledge, to date there has not been any involvement of lay people or patients in the design of virtual patients (VPs).

The aims of this work were:
• To design and build a novel virtual patient simulation, developing the dual skills of technical competence and interpersonal skills to make evidence-informed, shared decisions.
• To involve patient input in the design of the virtual patient simulation.

**Method**

A multistep approach was taken with the design.

**Literature**

The VP tool was based on existing literature and research about what broad features make for a good consultation, patient centred care and shared decision making. The most common consultation model in the UK, Calgary-Cambridge [33, 34], was used as a loose structure for the script. Its 70-items provided the skeleton and flow of the simulation. The technical/clinical elements are based on NICE guidance.

**Initial script drafting**

The initial script writing was completed by a pharmacist, medical doctor and medicines optimisation expert (SJ, NM and SC respectively). The script was a branched, multiple choice style; at each point the user had three options to choose from, what to say or do. There was then a corresponding patient response, and three more options presented and so on. The script was designed to allow the users to take circuitous routes through the consultation; for example, if early on, a key step is missed, the user could redirect the conversation back to pick up a key point.

**Patient involvement**

Local patient advocacy groups were contacted to identify interested patients. Each of the patients who agreed to participate were met individually and their initial ideas about the simulation discussed. Following drafting, sections of the script were shown to each person and comments elicited on realism and quality as well as any aspect of the script or simulation. Comments were collated and the script amended in light of the suggestions.

**Experts**

The final phase in the development of the design, before the animation element, was expert review. Three experienced primary care clinicians were asked to interact with a prototype version of the tool and provide written feedback on their thoughts; the prototype was devoid of animation. Comment was invited on the clinical aspects as well as those relating to pedagogy, such as the feedback. After the written reviews had been received these were collated and the necessary amendments to the script were made.

**Technical Details**

The script developed in these four stages was then built into a web-based virtual patient simulator; comment from patients and experts was only on the script and non-animated prototype, they did not review the animations and voice over elements. The table lists the particular specifications and products used to create the finished product.

<table>
<thead>
<tr>
<th><strong>Table 1 - Development software used</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Script Writing</strong></td>
</tr>
<tr>
<td><strong>Audio editing</strong></td>
</tr>
<tr>
<td><strong>Character/Environment modelling, rigging</strong></td>
</tr>
</tbody>
</table>
Results

The setting design was a primary care consultation room with the patient sat in front of you (see fig. 1). The user plays the role of either a GP or prescribing pharmacist, whichever is relevant to them. By selecting from the multiple-choice options, usually three each time, the user can navigate the scenario. After each option selection the patient will respond with a reaction using both pre-recorded speech and body language shown by high-quality animation. At the end of the simulation the user will receive feedback. The simulation will display on a computer, tablet or smartphone.

The comments on the design from both the lay people and the expert clinicians are tabulated below in tables 2 and 3.

<table>
<thead>
<tr>
<th>Lay Person Comment</th>
<th>Resultant Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referring to the patient’s age is not relevant; polypharmacy is most likely the reason for the patient not wanting to take more medicines which is irrespective of age</td>
<td>Referring to age at this stage led to a negative feedback point</td>
</tr>
<tr>
<td>An 84-year-old may well have hearing impairment so getting him to repeat back what changes he’ll make could be a way to check he has both heard and understood the discussion</td>
<td>A extra chain of options was included which allowed a user to choose to do this</td>
</tr>
<tr>
<td>There is no information on whether the clinician had met the patient before. Perhaps this information should be included at the start as it can affect the language used</td>
<td>This information was included and feedback amended</td>
</tr>
<tr>
<td>Patient background important as different cultures and ages affect communication</td>
<td>Background was made more comprehensive but this was balanced with reality; medical notes with full details of a patient’s social history was felt to be unrealistic</td>
</tr>
<tr>
<td>In the sections where risk/benefit of treatment was discussed, it was felt that the softer approach with less numbers was good and should occur more within the script. Flexibility was also felt important as if the user delved straight into statistics, they should be able to ‘rescue’ their attempt by providing a simpler follow up explanation</td>
<td>The possible route through the simulation was made more circuitous to allow users to make imperfect choices but then recover the situation later and vice versa</td>
</tr>
</tbody>
</table>

While not an explicit comment, many of the patients used the same words as the virtual patient used when replying to dialogue from the clinician; an encouraging sign that the language being used was lifelike.
<table>
<thead>
<tr>
<th>Expert Comment</th>
<th>Resultant Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>No option to use a patient decision aid (PDA)</td>
<td>The option to use a PDA was included</td>
</tr>
<tr>
<td>Very specific language used at certain stages e.g. different between 'something vs anything'</td>
<td>There is evidence to suggest subtle adjustments in language can have profound effects [35, 36]</td>
</tr>
<tr>
<td>There could be the option of a middle ground when presenting risk; current options are too distinct</td>
<td>A middle ground option was included so the choice of risk explanation language is not so dichotomous</td>
</tr>
<tr>
<td>If the case is handled very poorly, there is little feedback</td>
<td>More feedback was added in the event that a user handles the simulation very poorly</td>
</tr>
<tr>
<td>Feedback at the end is given too quickly</td>
<td>A pause was added between points and a written summary provided at the end</td>
</tr>
<tr>
<td>Whether the statin is for primary or secondary prevention is not clear</td>
<td>The patient’s medical history was amended to make it clearer</td>
</tr>
<tr>
<td>The supposed red flag symptom is not clear enough</td>
<td>A further bit of dialogue is added making the urinary symptoms more explicitly a red flag</td>
</tr>
<tr>
<td>Needs to be clear to the patient that we cannot predict whether they will or will not have a cardiac event</td>
<td>A line was added to stress that we cannot predict in advance whether any one person will have an event</td>
</tr>
<tr>
<td>No feedback for missing a potential red flag</td>
<td>Additional feedback was added</td>
</tr>
<tr>
<td>Wording of feedback could be more constructive</td>
<td>Rather than stating a negative piece of feedback outright phrases such as 'It was good you tried to.....but......' were added to make them more constructive</td>
</tr>
<tr>
<td>Medical notes not available from the start</td>
<td>Amended so the notes can be viewed at any given time</td>
</tr>
<tr>
<td>Might be useful to have a print out of the feedback for use in development portfolios</td>
<td>This function was added; a PDF of feedback can be downloaded each time the simulation is used</td>
</tr>
</tbody>
</table>

**In addition to the comments above, additional suggestions were made about the technical elements of the simulation; these were not enacted but are listed for future work**

| Feature a clock to show how long the consultation has been running, increasing the realism |
| The ability to go backwards in the consultation, re-trace steps |
| Have feedback given instantaneously, as the user goes along |

Due to this simulation trying to combine both technical and interpersonal competencies, as is the case for a real consultation, the feedback reflected this. The patient animation gave the emotional, softer feedback (e.g. ‘you made me feel comfortable’) and then the technical feedback was provided in written form (e.g. feedback on initiating a statin). This results from some of the comments in table 3. The feedback is exportable as a PDF to enable users to store a copy for use in portfolios.

To highlight the quality of the animation used, potentially important for the fidelity of the simulation, figure 1 shows a screenshot of the case.
To experience the VP simulator, we have created a short YouTube video to provide a brief demonstration; 'Virtual Patient Demonstration' [37]

**Discussion**

By incorporating patient opinion and shared decision-making principles, the resulting web-based virtual patient simulation simulated a clinical consultation congruent with a "real life" situation; the whole patient contact is simulated from calling the patient into the room, to the final remarks as they leave. Where a significant proportion of virtual patient simulations have sought to develop one skill or set of skills, the user of this software must draw on the whole array of abilities required for a competent, patient centred consultation.

A key difficulty in the initial phase of scripting, and indeed throughout, was the balance between the different multiple-choice options; one is good, one is bad and one is somewhere in-between. What constitutes wrong at one point in the consultation may be correct at another and as stated, users can make a wrong decision but still bring the consultation back to a good conclusion. The difficult task was to make all three options plausible, close enough together so that the choice is not obvious, but not so close so as to be a 'spot the difference' exercise, unless this was relevant. The patient involvement was very useful here.

Unpredictability emerged as a key theme during the patient involvement phase. It was a deliberate choice not to direct patients at the outset of their inclusion in the design process, allowing them to introduce elements which may not have occurred to the health care professionals in the design team. The authors, like all health educators and researchers, have a certain education, background and set of experiences which affect their perspective. Laypersons though have a different set of experiences which mean they can provide a different outlook or view on an issue. It is not knowable what this perspective will be and hence this is where the value of PPI or lay involvement is derived.

An early concern was that the patients involved would be overawed by the technology or the process and not feel able to contribute anything; the opposite was also feared, a situation where the patient did not understand the aim of the design and continually suggested inappropriate modifications.
What resulted was neither of these situations; all the patients clearly understood the aim and how they could assert their opinions and views.

**Conclusions**

Involving patients in the design of virtual patient simulations, particularly those involving any degree of communication has been shown to be useful for creating realistic scenarios. The outputs from the involvement of patients cannot often be predicted so it may well be a case of ‘try it and see’. While virtual reality simulations can be complicated and tricky to design, laypeople have the capacity to comprehend this and also contribute valuable ideas. We would recommend future virtual patient designers to at least consider patient/lay involvement in their designs.

A second conclusion is that it is possible to design a virtual patient that encompasses both the technical and interpersonal elements of care. Many of the previous architects of these technologies seem to have stuck to one or the other but to model reality more closely both have been combined in this design. What has been created is a web-based virtual patient to allow repetitive practice and feedback for evidence-informed, shared decision making. The next steps will be to evaluate and investigate the views of the target users, under- and postgraduate healthcare professionals.

**Acknowledgements**

Our thanks go to the lay and clinical experts involved in the design; their input was indispensable. We also thank the Digital Development Team at the Keele University School of Pharmacy for their work programming and animating the design.

If you wish to use the tool in your own teaching, please get in touch at s.jacklin@keele.ac.uk.

**Conflict of Interests**

The VP described in this paper is not licensed for commercial sale; none of the authors will therefore receive any monetary gain from the tool. SC is one of two patent holders for the technology. Keele University School of Pharmacy makes virtual patient products similar to the one described in this paper for a range of external commercial clients.

NM is a former Programme Director of the Medicines and Prescribing Centre at NICE and a current member of the NICE Shared Decision-Making Collaborative. SJ’s PhD is funded by a joint collaboration between NICE and Keele University. NICE had no input or control over the design of the virtual patient or the writing of this paper.

No other COI are declared.

**References**

4. Kon AA. The shared decision-making continuum. JAMA 2010;304(8):903-904. PMID: 20736477


11. Hong P, Gorodzinsky AY, Taylor BA, Chorney JM. Parental decision making in pediatric otoplasty: The role of shared decision making in parental decisional conflict and decisional regret. Laryngoscope 2016;126(S5). PMID: 27233057


14. Maskrey N, Gordon A. Shared understanding with patients. JAMA Internal Medicine, 2017;177(9):1247-1248. PMID: 28783822


30. INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research. 2012.


