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# Embedding an illustrator in the process of co-producing resources to enhance communication and shared decision-making for patients prescribed high-risk medication

Amelia Huw Morgan a, Delyth H. James b,\*

- <sup>a</sup> Cardiff School of Art & Design, Cardiff Metropolitan University, Cardiff, Wales CF52YB, UK
- b Health Psychology in Pharmacy Practice, Cardiff School of Sport & Health Sciences, Cardiff Metropolitan University, Cardiff, Wales CF52YB, UK

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#### ABSTRACT

Objectives: To examine how embedding an illustrator in the process of co-producing resources to support shared decision-making (SDM) can enhance communication between patients and healthcare professionals (HCPs). *Methods*: Three case studies were identified involving high-risk medications where the utility of effective visual communication resources is key to SDM due to the risk of information being misinterpreted leading to potential serious adverse effects. An iterative approach was adopted to the phases of co-production, where the Illustrator acted as a conduit between patients and specialist knowledge of the clinical team. The expertise of the Illustrator was harnessed to balance the use of visual and written information, working with the HCPs in co-creating the messaging.

Results: Case Study 1 relates to the urgent administration of hydrocortisone injection for adrenal crisis in adults and children. Case Study 2 relates to self-management of the need to adjust oral corticosteroid dosing during periods of adrenal insufficiency to prevent adrenal crisis. Case Study 3 focused on women with reproductive potential prescribed or considering sodium valproate for the management of epilepsy. The benefits of involving an Illustrator were evident across all case studies, invoking supportive, empowering and empathic visual communication throughout, leading to removal of some text by the clinical team.

Conclusions: Harnessing the expertise of Illustrators as part of a multi-disciplinary team with patients was seen as an enabler for authentic co-production to support an empathic approach to SDM in these three case studies. Further evaluation is needed to assess the impact of the use of visual communication resources of this nature in healthcare, and the impact on patient behaviours and clinical outcomes.

# 1. Introduction

Shared Decision-Making (SDM) is an interactive two-way collaboration between patients and healthcare professionals (HCPs), drawing upon medical expertise, best evidence while incorporating the patient's values, views, and preferences [1]. Various models have been adopted to underpin strategies to support SDM [1–4]. Engagement in SDM requires open, honest and empathic communication embracing patients' lived experiences, cultural differences and health beliefs, whilst targeting their personal needs [1–8]. These emphasise the need to discuss treatment options, create choice awareness, elicit patient preferences, and tailor information, to incorporate patient perspectives into the

therapeutic plan [5]. Therefore, SDM requires a system of information exchange that evokes a strong connection between the patient and HCP. While considerable efforts have been made to improve consultation skills of HCPs to embrace this approach [6,7,9], less is known about the factors that contribute to patient participation in SDM [8].

Access to decision tools which guide patients through the process of SDM is important [10], especially where there is potential for miscommunication or misinterpretation of information. These barriers can be overcome by involving a professional Illustrator in the co-design of resources to support SDM. Illustrators bring empathy and expertise to the co-production process and can optimise the development of resources to support patient engagement in SDM.

E-mail address: dhjames@cardiffmet.ac.uk (D.H. James).

<sup>\*</sup> Correspondence to: Cardiff School of Sport & Health Sciences, Cardiff Metropolitan University, Llandaff Campus, 200 Western Avenue, Cardiff, Wales CF52YB, UK.

A review of the literature found that whilst the use of illustrations and images to enhance visual communication was evident [11-14], there is a paucity of published work involving Illustrators. This paper aims to examine how embedding an illustrator in the process of co-producing resources to support SDM can enhance communication between patients and HCPs.

#### 2. Methods

An iterative approach was adopted to the phases of co-production, where the Illustrator becomes a conduit between the patient and specialist knowledge of the clinical team. Three case studies involving high-risk medications were identified where the potential risk of information being misinterpreted was high.

Case Study 1 (CS1) was the administration of hydrocortisone intramuscular injection (for adults and paediatrics) during episodes of adrenal crisis. Case Study 2 (CS2) was recognition of symptoms and self-management of oral corticosteroid dosing adjustments during periods of adrenal insufficiency. Case Study 3 (CS3) focused on women with reproductive potential prescribed or considering sodium valproate for the management of epilepsy.

Whilst a variety of different written materials exists for these medications, they tend to contain large amounts of text with minimal visuals. The information is impersonal and not presented in a way that is engaging for the patient to take part in making decisions about their own management. An inter-disciplinary approach was taken, where Illustrators collaborated with patients, clinical specialists (medical, pharmacy, and nurse practitioners) and health psychologists to codesign visual communication SDM support tools.

Fig. 1 shows the six-step iterative approach applied to all three case studies. Step-1 involved the conception of the idea where a high-risk area was identified. Step-2 involved a process of knowledge exchange where HCPs with specialist knowledge and patients' lived experiences were shared with the Illustrator and the multi-professional team. Step-3 is building trust, where draft illustrations are shared to gain initial reactions. Step-4 deals with enhancing communication in response to initial feedback. Step-5 refers to the process of ensuring that empathy is maintained, capturing feedback from patient groups (via focus groups or one-to-one interviews). Step-6 involves re-balancing the power dynamics to ensure effective integration of illustrations into visual communication resources, which may involve repeating Step-5. University Ethics Approval was required for the latter two-steps (CS1&2-

PGT-5783; CS3-PGT-6089/Sta-9015).

#### 3. Results

CS1: The aim was to help patients, and their support networks know when and how to recognise and respond to the symptoms (or potential symptoms) of adrenal crisis and administer a hydrocortisone intramuscular injection correctly and confidently. Strong concerns were expressed during focus group discussions with patients about the fears of administering the injection when not appropriate. During an episode of adrenal crisis, the right decision is always to administer the injection, since not doing so or any delay so could lead to death. The illustrations enable a decision to be made in a way that is not frightening, instilling confidence in those who might be required to administer this lifesaving medication, making it clear that no harm is incurred from administering it. Key to the illustration process was empowering a measured approach to a situation requiring calm and direct action (Inj Adult; Inj Paed).

CS2: The aim was to help patients manage their steroid medication and adjust their doses as appropriate for everyday scenarios (such as going on holiday, sickness etc.) to prevent getting to the stage of adrenal crisis. The booklet was co-created in such a way to help patients navigate the plethora of information in an engaging way. During co-creation it was evident that patients knew they were unlikely to retain all the information, but could refer to it later if they felt unwell (AI Booklet). The character of a bird presents the narrative within this lengthy (44-page) booklet to guide the patient, portraying the essential information by telling a story, whilst highlighting the serious signs and symptoms to look out for in adrenal crisis.

CS3: The purpose was to provide information about the risks and benefits of taking valproate, emphasising the need for highly effective contraception or alternative anti-seizure medications. What patients need to know and what they take away from a consultation may be very different. A patient might misconstrue being told 'You can't get pregnant on this medication' as not being able to conceive (i.e. not needing contraception) as opposed to being associated with the risks to the unborn foetus. Accessing this booklet before an appointment, can encourage patients to reflect on the information and formulate questions in advance (Valproate). This patient decision aid helps women and girls make the right choice for them whilst providing a framework to guide consultations of specialists who prescribe Valproate.

For all three cases studies, Illustrators used calm, soft colours, invoking positive, supportive, encouraging and empathic visual

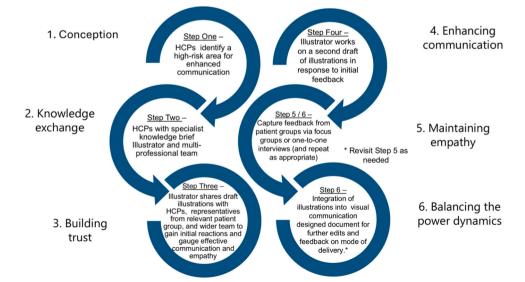


Fig. 1. Flow diagram to illustrate the integration of steps involved in the iterative co-design process, goals of each stage of intervention co-development and method of delivery.

language throughout. The addition of key illustrations led to further removal of some aspects of the text by members of the clinical teams.

#### 4. Discussion and conclusion

#### 4.1. Discussion

This paper described a novel multi-disciplinary approach to coproduction of visual communication resources to support SDM for the safe and effective prescribing of high-risk medicines. Embedding an Illustrator within the inter-disciplinary teams, brought clarity to the delivery of complex information in a holistic way, to enable better patient understanding. The resultant material provides a generic framework which can be used in clinic settings during consultations, and for patients to refer to prior to attending appointments. Fostering an environment where the patient feels enabled to play an active role in the consultation can support patients to feel more control over their condition [15].

The strength of this approach was in the role of the illustrator who acted as a conduit, visually conceptualising the patient's lived experience through empathetically produced illustrations, simultaneously positioning lived experience in the clinical context. Patient feedback in *CS1* reinforced the significance of using effective illustration to reduce any fear arousal which may lead to a non-communicative response [16, 17]. This process ensures that empathy is at the heart of co-production where respect for all parties involved is central to the process.

We have gained positive qualitative feedback from patients and HCPs about the process and outputs of this work, however, the impact of these visual communication resources on patient behaviours and clinical outcomes have yet to be evaluated. However, through these examples, we have shown that these illustrative resources form the basis for building a robust framework for important communication, prioritising high-risk medicines and their implication for patients' everyday lives. This approach has the potential to be applied to other therapeutic areas where SDM lies at the core of adherence to treatment recommendations which lead to successful health outcomes. Further research is needed to explore the impact of accessing these co-produced illustrative resources to support SDM in practice.

#### 4.2. Conclusions

In conclusion, harnessing the expertise of Illustrators as part of a multi-disciplinary team with patients was an enabler for authentic coproduction to support an empathic approach to SDM in these three case studies. The power of illustration, when created with purpose, respect, understanding and empathy at its core (from the perspectives of the patient and the HCP), is fundamental to, and provides a highly effective approach to, clear communication, potentially leading to better health outcomes. Further evaluation is needed to assess the impact of the use of visual communication resources of this nature in healthcare and its impact on patient behaviours and clinical outcomes.

## 4.3. Practice implications

The three examples highlight the utility of illustration in supporting the roles of the HCP and patient equally, with the goal of providing agency for the patient to feel capable of taking responsibility for their own health. Time constraints and lack of resources have been identified as barriers to HCPs engaging in SDM [18,19] which could be allayed by adopting the use of visual communication resources such as those described. Furthermore, a phenomenon, known as 'decision-fatigue' [20] has been noted where doctors prescribed more unnecessary antibiotics later in the day due to mental fatigue [21]. We propose that authentically codesigned illustrations of this nature can support busy HCPs in communicating complex, detailed information with clarity and care when working in highly pressured environments, helping to retain

the human connection when addressing the needs of the patient.

#### CRediT authorship contribution statement

Amelia Huw Morgan: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Project administration, Methodology, Conceptualization. Delyth James: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

#### **Author contributions**

Both authors (AHM and DHJ) contributed equally in terms of conceptualisation, writing and reviewing the manuscript.

#### **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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