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VALUING THE DESIGN PROCESS IN HIV PREVENTION, DIAGNOSIS AND STIGMA

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ABSTRACT *A group of health workers and designers teamed up to develop novel ways to respond to HIV prevention, diagnosis, and HIV-stigma challenges. They integrated creative, participatory, user-centred design skills with scientific and clinical expertise to address emerging challenges. This paper explains how this interdisciplinary collaboration evolved, reflecting on how a design centred approach is valued and influences collaboration and outcomes in health projects. The research explores three projects in which design tools and methods such as user workshops, user journeys, scenarios, personas and interaction mockups were employed.*

Project one aimed to develop a pilot service to encourage HIV self-testing among men who have sex with men (MSM). It included a series of design workshops involving members of the LGBT community and People Living with HIV (PLWH). The final design involved the building and testing of a bespoke vending machine to distribute free self-test kits, and of its digital interface. Project two aimed to develop a programme/campaign to increase HIV testing rates in general practice surgeries in Brighton and Hove. Project three, intended to reduce HIV stigma & discrimination using digital resources disseminated via social media platforms.

The paper identifies critical aspects emerging from the collaborative design process, shows how it is valued by health workers and demonstrates how the utilisation of a design centred approach enables creative responses and facilitates collaboration and user involvement in the context of HIV prevention, diagnosis and treatment.

Keywords: design, health, HIV, collaboration, design process, interdisciplinary



Introduction

Advances in the management of HIV have transformed HIV disease from a fatal condition to a chronic disease with a life expectancy similar to that of the general population, Katz and Maughan-brown (2017).

The introduction of antiretroviral therapy and pre and pro exposure prophylaxis has had a significant impact on the improvement of the life quality of people living with HIV and helped in controlling the spreading of HIV. As a result of these developments and other prevention strategies, the incidence of HIV in the United Kingdom is decreasing, Public Health England (2017).

However, information about how these advances have transformed HIV have not been disseminated. HIV stigma remains a significant problem for people living with HIV and remains a barrier to testing, preventing key populations from accessing diagnosis and treatment services. Data from Public Health England (2016) suggest that there are over 13.000 people in the UK that are unaware they are HIV positive.

Although there has been a substantial increase in testing options available to MSM (Men who have sex with men), they still face barriers hindering access to testing including stigma, confidentiality concerns and health service issues such as delays getting an appointment in clinics for testing. Similarly, misinformation, prejudice and ignorance in broad sectors of the population lead to the stigmatisation of individuals living with HIV, depriving them of a regular and fulfilling life.

This estate of affairs reveals the need for a creative approach beyond traditional medical research boundaries. Interdisciplinary collaboration between health professionals and designers seems to be a reasonable approach to address the complex and socially laden issues of HIV diagnosis and stigmatisation.

The benefits and shortcomings of collaboration between designers and scientists (included medics) have been studied in the context of scientific research, Peralta (2013). There is a plethora of scholar research reporting individual cases of collaboration between designer and doctors, but little evidence of it in the context of HIV research.

Some of the few existing examples include the work of Bennett et al (2006) exploring participatory design methods with participants as co-designers of an HIV/AIDS visual campaign in Kenya, or Van Deventer, Robert, and Wright (2016) research examining co-design methods involving mothers of HIV positive children and health care workers to improve

healthcare services. These investigations look at the value of participatory design approaches, but do not reflect on the design process as a whole, or discuss the collaborative process between designers and health workers.

This research responds to this gap by reporting on how health professionals and designers can team up to address the challenges presented by HIV diagnosis and stigmatisation, making explicit the value of the design process within this collaboration, arguing that designers and health experts disciplinary roles are complementary and favour the success of collaborative endeavour.

Although there are many potential ways of describing the design process, Dorst and Dijkhuis (1995), this paper assumes that the design process is formed by all the interconnected actions designers carry on to generate a design proposal. It adheres to Stolterman and Nelson (2012) p. 75 characterisation of it as ‘both systemic (integrative and interconnected) and systematic (methodical, sequential, and episodic)’. However, this paper recognises that the design process is not necessarily a sequence of events, but rather a ‘System of spaces [...] [that] demarcate different sorts of related activities that together form the continuum of innovation’ p.4 Brown (2008)

METHOD

This research draws its conclusions from the views of a team of HIV experts, clinicians, designers and a social sciences researcher who for their first time, engaged in a four years collaboration with two designers in three projects as illustrated below:

HIV PROJECTS & TEAM MEMBERSHIP










PROJECT \ TEAM MEMBERS	 Designer A	 Designer B	 HIV Expert A	 HIV Expert B	 HIV Expert C	 Clinician GP A	 Clinician GP B	 Social sciences Researcher	 Patients Representative
1 Pilot project of a Digital Vending Machine for distribution of HIV Self- Testing kits	✓	✓	✓	✓	✓				
2 Development of a programme to increase HIV testing rates in general practice surgeries in Brighton & Hove	✓	✓	✓	✓	✓	✓	✓		
3 Using digital platforms for a campaign to reduce HIV stigma and discrimination	✓	✓	✓	✓				✓	✓

Table 1: HIV projects and membership

The data from the HIV experts and clinicians was obtained through individual written interviews. They were carried out via email, and the interviewees had the opportunity of asking questions before submitting their answers.

Using open-ended questions, the interviews were designed to explore the interviewees' views about their **experience** of working with designers, their thoughts about designers' **expertise** and **working practices**, and the **value and usefulness** of working with designers.

Data was also collected during participant observation (as the researchers of this investigations are the same designers of the collaboration) and discussion sessions between them.

THE PROJECTS

Three projects were carried out during four years as illustrated in diagram 1.

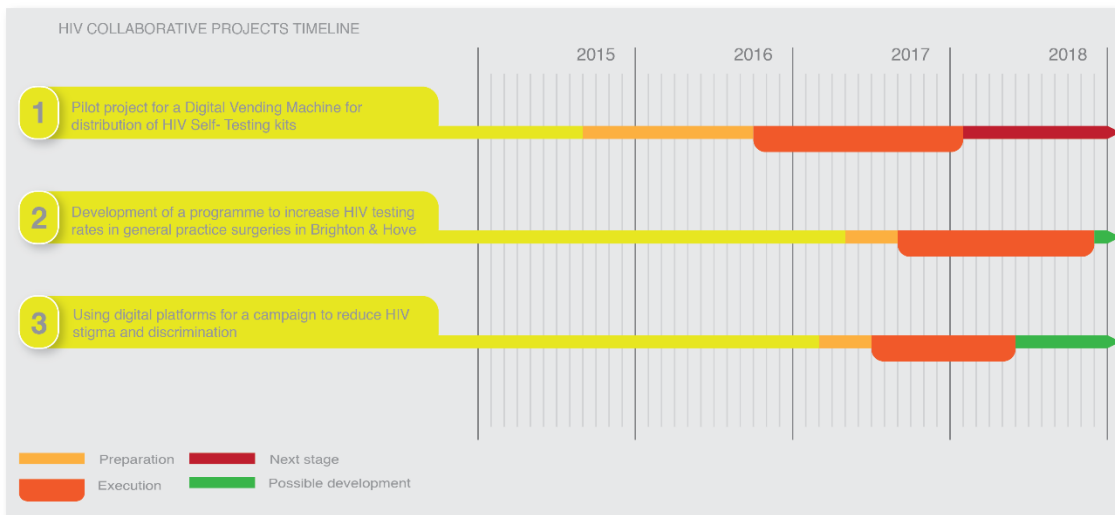


Diagram 1. HIV collaborative projects timeline

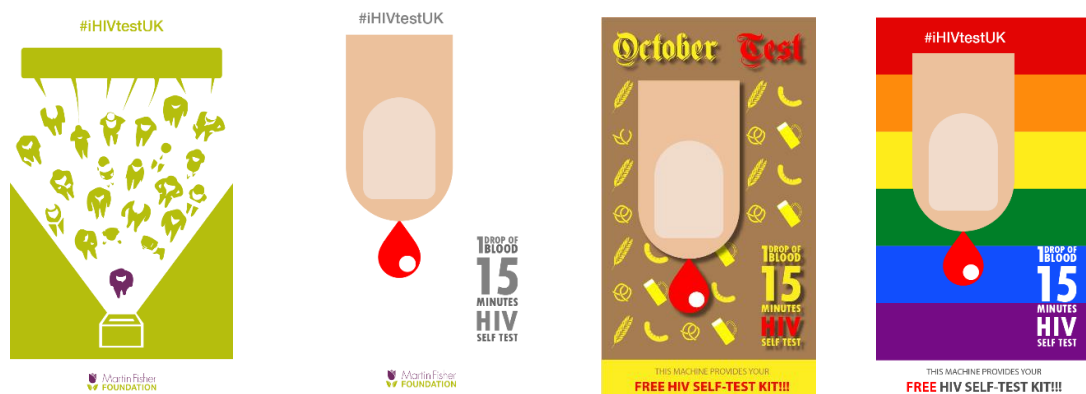
Project 1 Pilot project for a Digital Vending Machine for distribution of HIV Self- Testing kits

The project aimed to enable the procurement of HIV self-test kits through vending machines in popular venues to high-risk MSM. It involved the design, customisation, installation and testing of an HIV self-testing kit vending machine, and of a user support platform.

The project development team included four HIV medicine experts and two designers with experience in product, interaction and services design.

Design process

The design process started with the outline of a design brief, followed by the development of initial visual concepts (to be embedded in the machine interface) to encourage the use the machine, and a proposal for its interface. After this, participatory design workshops with members from the LGBT community to evaluate and improve the visual material and the machine interface took place. The final design of the machine layout and its interface was developed, followed by the design of leaflets to inform patients what to do after testing. The design process concluded with the design and production of screen-based seasonal promotional posters.



Picture 1. Examples of visual elements for machine promotion



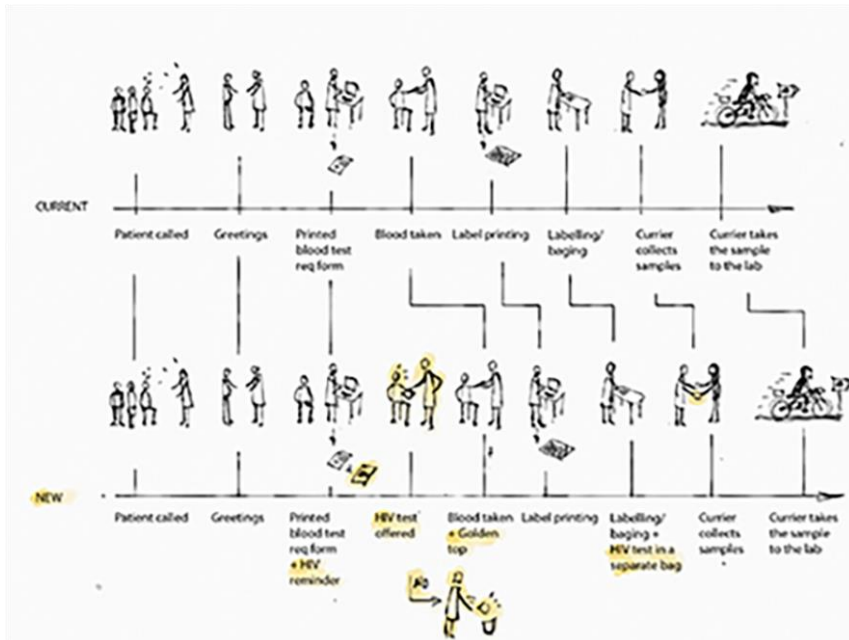
Picture 2. Vending machine in the context

Project 2 Development of a programme to increase HIV testing rates in general practice surgeries in Brighton & Hove.

The project intended to develop a pilot programme to support behaviour change around HIV testing in the general practice workforce, encouraging GP patients to test for HIV. The programme was developed in three GPs located in Brighton & Hove by two clinicians champions working alongside a team of HIV expert clinicians and designers. After the team realised that the potential increment in HIV testing through GP practices would strain testing labs capacity beyond their limit, the project refocused on the creation of a lobbying campaign addressed to stakeholders and decision makers, to promote the advantages of the programme, and secure additional funding.

Design Process

After outlining a design brief, designers carried out non-participant observations in three GP practices. They observed patient behaviours in reception and waiting areas, witnessed live blood sampling and interviewed nurses and phlebotomists. Designers created a patient/user journey and designed alternatives for a campaign aiming to incentivise patient requests for HIV test, based on visual material and new protocols of interaction, including the development of a campaign 'motto' and a logo. As the clinicians learnt from the labs' difficulties to respond to an increased amount of tests, they refocused priorities. Then the designers, based on their patient/user journey, developed an animation to explain the proposed changes in blood testing protocols suggested by the clinicians.



Picture 3. Diagram of the current and proposed patient/user journey



Picture 4. GP's campaign visual material proposals

Project 3 Using digital platforms for a campaign to reduce HIV stigma and discrimination

The project aims to reduce HIV-stigma by creating a digital anti-stigma campaign relevant to the general population, including illustration, animation and video. The content of videos and campaign messages are the result of a series of participatory design workshops with people living with HIV and from the general population.

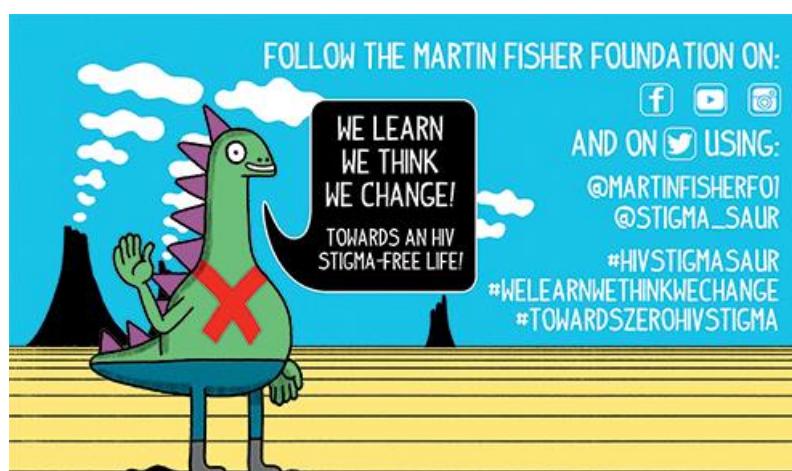
The project team is formed by three HIV expert clinicians, one social scientist, two designers specialised in product/service design and a patient representative living with HIV.



Picture 5. Illustration by a designer of a workshop participant's insight

Design Process

It started with three participatory workshops where people living with HIV and members of the general population expressed their experience and views about HIV stigma. Using design tools such as Personas, scenario building, storyboard writing and cartoon drawing, participants develop key ideas and scenarios which became the basis for the campaign, and for the designers' concepts and scripts for the campaign videos. Designers defined guidelines for the video producers, briefs for the illustration and animation team. Alongside the patient representative, designers also created other campaign elements such as pins, T-shirts, fliers, etc., and visual material for social media.



Picture 6. Campaign character 'The HIV Stigmasaur' in a promotional flyer.

RESULTS

The research results show medics perceptions of their **experience** of working with designers, their views about designers **expertise and working practices**, and their appreciation of the **value and usefulness** of design and the design process.

Perceptions about how different was for them to work with designers in comparison to work with colleagues from their disciplinary area (experience)

HIV experts perceived noticeable differences in working with designers. For example, one of them said that it opened his mind to a different world, noticing that designers creative focus contrasts with doctors', which is centred on practicalities and 'technical stuff'.

Other clinician explained that working with designers enables doctors to have a say on the design of materials and on what is the best moment to 'get them across to patients'. He described the experience as an iterative process of development.

Another doctor observed that working with designers requires extra time to explain what they are trying to achieve, what is possible, and what clinical aspects are relevant. Relatedly, other doctor commented on the designers' lack of technical vocabulary and the need for doctors to speak to designers in 'lay' terms about medical concepts.

Other doctors highlighted how designers make look things 'professional' and how they learnt from them the importance and complexity of visual communication. She also noticed how designers seem to have a 'greater need to understand [processes]'.

Views on the design process and how it influenced their collaborative project (working practices/value/usefulness)

Most doctors comments on the design process focused on its usefulness or about specific parts of it. A doctor found interesting the use of research with users (through workshops) to underpin design work. Similarly, another doctor commented on how designers acquired knowledge of user journeys based on first-hand observations.

Even if doctors seem not to know much about the design process, they recognised the importance of it in the projects. This becomes evident in statements such as 'now, every time we need to develop something, we always think, oh, do we need a designer?'

Perceptions on what designers know and what they do (expertise)

Doctors were unsure about what designers know, but they recognised some of their skills:

- Making medical information accessible and appealing to services user.
- translating medics ideas into a design
- being the interface between clinical staff and patient, giving patients a better understanding of medical issues
- 'targeting materials' to achieve project's goals based on their good understanding of projects' goals
- Noticing if things look right or not
- Doing 'lots of research/communication before producing the end product [to ensure] it is fit.'

They also named some of the tools designers employed:

- Digital printing and drawing.
- Co-design workshops
- Props and make-ups

Ideas about the main challenges of collaborating with designers (experience)

Doctors identified several challenges to collaboration. They expressed problems about logistics such as finding suitable meeting time and premises. They highlighted the importance of understanding 'each other's work pressures [and the] need to have clear timescales of meetings given business of diaries'. They also stated the need for having regular communication, and face to face meetings, especially when discussing designs.

Medics underlined the importance of ensuring designers understand the project 'background' and are made aware of the project context and issues. Medics noted that differences in language (including technical vocabulary) and assumptions by doctors about designers knowing what they (the doctors) know could be problematic.

Qualification of their experience of working with designers (value/usefulness)

Medics' qualified their experience of working with designers as positive, using words such as fun, exciting, rewarding and interesting. They referred to the effect the collaboration produced on them as enlightening and eye and mind opening. They also reflected its usefulness, describing it as a learning, helpful and constructive experience.

They linked their evaluation to certain designers' traits such as attention to detail, thoughtfulness, clarity, knowledgeability and professionalism, mentioning designers readiness to challenge the team when appropriate.

Perceptions of the influence that working with designers might have had on their ways of working and thinking (value/usefulness)

Medics reported that working with designers have changed their way of thinking and approach to work, noticing how they now look at patients interactions with the health system as identifiable and mappable processes. They also acknowledged the importance of involving and consulting with patients before changes are made. As expressed by one of the clinicians, there is a 'need to understand the process (however simple it might seem – there are always extra insights to be uncovered) and involve patients -always'.

Doctors have also changed their communication approach, giving more importance to the use of visual materials when interacting with other colleagues and project stakeholders. A one them states, 'I recognise that when it comes to learning, visual aids and videos are much better



at getting the point across than just talking to people! Also having material and logos make your project look important - and people are more likely to take notice with an eye-catching logo and professional material.'

DISCUSSION

The findings of this paper show how working with designers can be perceived as a positive experience by medics, how different but complementary designer and medics expertise is, and how useful design can be to address issues related to HIV prevention, diagnosis and stigma.

The experience

Collaborating with designers is not something HIV doctors are used to. However, the findings reveal doctors' positive outlook about it, as it brings them new and complementary skills to help to realise their ideas, exposing them to fresh and different points of view, which also supports the improvement of their ideas and the generation of new ones.

Even if designers and scientists learn from each other during collaboration, the findings show that both doctors and designers continue performing within their respective disciplinary boundaries. However, there are cross-disciplinary influences, especially when designers and doctors adopt each other languages. This is also noticeable, as stated by some of the doctors, in their progressive adoption of the designer's process and system thinking.

This research has also shown that the initial lack of a common working language between designers and medics is a barrier to collaboration in HIV related project, and that time and effort is required by doctors and designers to overcome it. While doctors need to find less technical ways of expressing medicine-related themes, the designers should attempt to explain their specialised vocabulary to doctors, especially about their tools and processes.

Different and complementary skills

It is apparent that design skills are complementary to those of medics. This can be understood by considering the work medics do in the HIV context. Other than seeing patients and undertaking scientific research, doctors are often involved in the development of initiatives for the improvement of the quality of the service they provide, and the pursuit of behavioural change in patients, health workers and the general population. These



activities not only require expert knowledge of HIV but a deep understanding of how their patients interact with the health service and the society.

In this sense, designers user centred approach and skills are useful and complementary to doctor's, as they enable the understanding of patients as service users. Participatory design workshops, personas, scenario building and storyboard development, give doctors and designers access to patients experience an opinions.

It is also important to consider that some of the innovative ideas medics may have probably come from their day to day experiences and subject knowledge but might not have been sufficiently considered regarding the systems they are part of or the processual implications they might have. Designers system thinking skills, combined with a service design approach complements the experience and knowledge of doctors making available tools such as user journeys and experience mapping, to render doctors' ideas compatible with existing or future systems and processes.

Another aspect of this complimentary skills match can be explained by highlighting the processes by which doctors undertake their development activities. Any initiative of change they might want to pursue needs to go through a rigorous vetting process, where scientific, practical, ethical, institutional and economic considerations are paramount. This involves the procurement of research-based written evidence to justify their initiatives, and a series of communication activities to present their ideas to colleagues, patients, and other stakeholders. Designers' ability to develop visual material not only helps them to convey their ideas in a more precise manner but adds an element of professionalism to their presentations that can, as one of the medics expressed, increase credibility. An analogy that might sum up the value of the design process in HIV research is the one of a puzzle (collaborative endeavour), where all pieces (doctors and designers skills) complement each other. The following diagram 2. illustrates it.

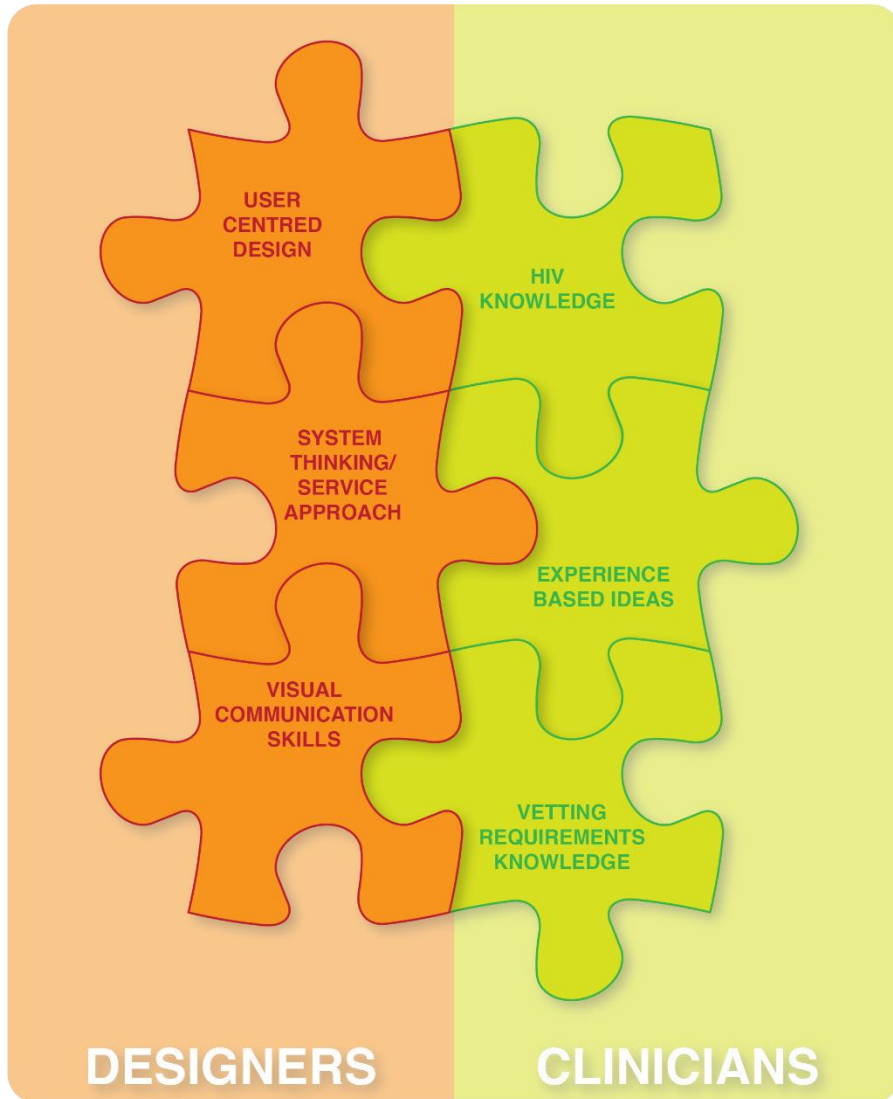


Diagram 1. HIV collaborative projects timeline

CONCLUSIONS



This research showed how doctors could recognise the usefulness of the design process through the identification of specific design skills and expertise. However doctors' appreciation of the design process as a holistic approach to address issues related to HIV prevention, diagnosis and stigma is still uncertain.

Perhaps this can be explained by the contrasting differences between the scientific approach of medics and the designerly approach of designers.

The medics want a clearly articulated, transparent process that can be held up to scrutiny and examined from beginning to start so that any potential weaknesses or stress points can be eradicated or tested out in advance. Fully knowing the process is essential to them.

In contrast, the designers do not know in advance; they trust their process and the interaction it will produce. They trust –because it has happened many times before – that if they create the conditions, an outcome will emerge that is born from those conditions, but which cannot be known in advance.

This is a most significant difference. The difference in process and knowing/not knowing outcomes. On this point, doctors and designers need to learn to trust each other and share enough to reassure but still give each other space.

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