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A holistic outcome-based approach to co-create healthcare systems.

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Abstract: Healthcare needs to be delivered more holistically, in a way that addresses outcomes for different stakeholders at different levels. Systems thinking has conceptually helped the understanding of the increasing complexity of healthcare outcomes. However, little consideration has been given on how to practically apply this concept to holistic outcome understanding to (re)design healthcare systems. Therefore, this paper aims to develop and evaluate a holistic outcome-based approach to healthcare systems co-creation. Participatory mapping workshops and interviews to co-visualise outcomes as an interconnected system were conducted with two groups: twenty-three design practitioners/researchers and twenty-one patients and healthcare service providers. Results emerged from network analysis which identified critical outcomes, disagreements, gaps and opportunities for system (re)design. The results demonstrated the potential role that this approach could have in gathering, communicating and negotiating the complex needs of multiple stakeholders for healthcare system (re)design.

Keywords: systems thinking; participatory design; systems visualisations; healthcare outcomes

1. Introduction

The healthcare system faces enormous pressure to address complex needs with a holistic paradigm (Norris et al., 2019). Attempts to achieve this holistic vision have resulted in the inclusion of strategies beyond the traditional scope of healthcare, which include multiple stakeholders (Herbert & Best, 2011). Personalised care plans and community care are good examples of current areas aiming to deliver holistic care.

This expansion of strategies and stakeholders involved in healthcare has increased the complexity of outcomes that need to be addressed. Outcomes can include biometrics and meaningful aspects of life, such as wellbeing, but also broader parameters of integrated

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working and safety (de Silva, 2014). These outcomes bring new challenges for healthcare, which needs to account for all these aspects as a whole interrelated system.

Systems thinking is a suitable paradigm to tackle complex challenges in healthcare (Braithwaite et al., 2018; Wilkinson et al., 2018). Applying systems thinking in healthcare can increase the holistic understanding of the systems, challenge assumptions, embrace flexibility and adaptation, and promote leadership models to redistribute shared decision-making (Khan et al., 2018; Paina & Peters, 2012; Peters, 2014; The Health Foundation, 2011). Nevertheless, more is needed to embed the complex understanding of systems into practical applications in healthcare (Rusoja et al., 2018). Furthermore, there have been few empirical pieces of research which consider how an understanding of multiple outcomes can play a role in enhancing healthcare systems.

Some systems thinking frameworks have created synergies with design to mitigate those gaps (Holden et al., 2013; Jones, 2014; Read, Salmon, Goode, & Lenné, 2018). Design has contributed to more practical strategies for deeper engagement and collaboration with multiple stakeholders to co-produce interventions (Tseklevs & Cooper, 2017), and has refined visual strategies to manage and communicate complex messages (Sevaldson, 2018). Of note, the most effective systems thinking actionable strategies have been determined by iterative design processes of co-creation (Jones, 2014). Therefore, it seems appropriate to explore how a holistic understanding of outcomes can be translated into more actionable strategies for co-designing healthcare systems.

This paper aims to develop and evaluate a holistic outcome-based approach to healthcare system co-creation. The term “holistic outcome-based” refers to including a variety of meaningful outcomes for different stakeholders, mixing objective/subjective, self-reported, anecdotal, and quantitative/qualitative elements. Due to the still exploratory scope of this study, the “healthcare system” boundaries to apply this approach remain flexible. Chronic care services have been selected in this study because they demand the integration of different organisations and societal structures, expanding the range of outcomes and stakeholders involved. Finally, “co-creation” refers to the participation of different stakeholders in (re)designing the systems.

To achieve these aims, this paper presents a review of the concept and role of outcomes in healthcare, and how other approaches have supported their understanding and application. Then, the development process of the holistic outcome-based approach is presented; this development has followed the five steps of the Design Research Methodology (DRM) (Blessing & Chakrabarti, 2009). Next, the findings from using the new approach in two cases are presented. Finally, this paper discusses how the holistic outcome-based approach is a promising system thinking framework, which can be used to gather, communicate, and negotiate the complex/multiple needs of different stakeholders for healthcare system (re) design.

2. The role of outcomes in healthcare systems design

The concept of ‘outcome’ demands a reconceptualisation in order to integrate considerations from contemporary approaches and systems thinking perspectives (Paterson et al., 2009). Conventionally, an outcome is described as the result of a *visible* effect that is seen after some explicit *action*. In healthcare, an outcome is associated with quality, and it is generally expected to be positive. The actions needed to trigger an outcome are frequently known as interventions. (Davies & Crombie, 1997; Starfield, 2001). Therefore, providers ‘prescribe’ an intervention for achieving (positive) outcomes. Nevertheless, this concept of outcomes denotes a narrow and linear approach.

Although the inclusion of psychosocial dimensions and patient-reported outcomes (PRO) such as quality of life had generated a more robust approach in later years, outcomes emerge mostly from the provider’s perspective. For example, PRO tend to be employed infrequently, even if they are a valid method for evaluating healthcare quality interventions and provide better information for policy decision-making (Black et al., 2016). Therefore, more qualitative or ‘anecdotal’ data is required to expand the type of evidence in healthcare. This evidence should consider a broader range of human attributes that can be translated into outcomes (Black et al., 2016; McConachie et al., 2018; Reuben & Tinetti, 2012). Healthcare studies have recognised that a broader range of outcomes that reflect meaningful human aspects beyond health settings and trial studies are needed (Lewis & Killaspy, 2014). Therefore, this holistic outcome-based approach champions for the integration of a rich mix of outcomes.

2.1 Outcomes in systems frameworks

Although outcomes are common elements in healthcare and systems thinking approaches, they have received only minor attention in design literature. Existing research has highlighted the need to understand outcomes for developing better systems (Flemming, Booth, Garside, Tunçalp, & Noyes, 2019; Petticrew et al., 2019).

Cognitive Work Analysis (CWA) has provided a more protagonist role of outcomes. CWA proposes a means-ends structure to understand systems. The five-level structure is formed by purpose, outcomes, functions, processes, and objects (Naikar, 2017; Rasmussen et al., 1994); this structure helps to identify why and how something occurs. Also, CWA has created traceability from outcomes to the purpose and functions of the systems. However, the application of CWA to directly inform design requirements is scarce. A CWA design-oriented toolkit has been used satisfactorily in transport contexts (Read et al., 2018), but there is not yet the evidence in the healthcare context. Authors acknowledge that the toolkit still needs exploration to “generate designs for first-of-a-kind systems” (Read et al., 2018). Additionally, there is an opportunity to expand this toolkit with a specific tool to tackle the outcome level in-depth.

Outcomes are also part of well-known healthcare frameworks. The Systems Engineering Initiative for Patient Safety (SEIPS) configures healthcare into three major components: work system, processes, and outcomes (Holden et al., 2013). In SEIPS, outcomes are indicators

of performance that represent stakeholders' goals. Outcomes play the role of moderating the adaptation of the system through feedback loops. Identifying unanticipated, reactive and intermittent outcomes helps to adapt and reconfigure the system (Holden et al., 2013). SEIPS have refined the categorisation of outcomes through its three different versions. The latest SEIPS 3.0 (Carayon et al., 2020) employs patients, caregivers, clinicians, and health organisations as categories. Despite its benefits, the authors of SEIPS have pointed out that its descriptive scope does not provide critical elements for action, nor does it deliver multiple views of outcomes to provide a holistic perspective of adaptation. Consequently, they appeal for the development of supportive toolkits to implement the model in healthcare (Carayon et al., 2006; Holden et al., 2013). Another relevant framework in healthcare is the Quadruple Aim (Sikka et al., 2015) which emerged from the Triple Aim (Berwick et al., 2008). The aims of this approach are better health, better care, lower cost, and better staff experience. The Quadruple Aim strengthens the concept of goals as interdependent elements, and the function of integrated care. The Patient Priorities Care (PPC) framework helps patients to identify their priorities based on their outcome goals and their trade-offs (Feder et al., 2019). PPC defines a four-step process to help patients define their most desired outcomes based on their values (Naik et al., 2018). PPC has helped patients to understand outcomes, goals and objectives differently, resulting in better-integrated care.

Finally, Systemic Design has identified principles such as 'purpose finding' and 'idealisation' that are related to the role of outcomes. First, the purpose finding principle is an abstract function that defines the whole system (Jones, 2014). A well-defined purpose will help to guide and align actions. The purpose often gives rise to a series of ideals, goals and outcomes. The idealisation is the principle of identifying actions and conditions to achieve a desirable outcome (Jones, 2014). This principle turns Systemic Design processes into a more future-finding approach. Furthermore, Systemic Design has highlighted how stakeholders act based on individuals' concerns and their own values to achieve outcomes, rather than a shared understanding of collective discrepancies (Jones, 2014). Outcomes have not been explicitly revised by Systemic Design. Still, some systemic-oriented authors such as Dorst (2019) consider outcomes to be the result of a reasoning process (how) that connects elements of the world (what). Other authors suggest that outcomes are "a product"; hence, outcomes can be desired and sought (in purposeful systems). However, outcomes can be emergent and unintended. Jones (2014) also advised that "the four orders of design (communication, artefacts, services and complex systems) represent possible outcomes for designed functions".

In summary, these approaches have recognised how outcomes directly inform the purpose of the system and how outcomes foster adaptive system behaviour. However, those abstract functions have remained distant from more practical applications. An outcome-based approach could support early discussions/encounters with a variety of stakeholders. Those discussions will integrate an initial vision of the system that aligns the (re)designing and supports a holistic decision-making process.

3. Methodology

This research aims to develop and evaluate an approach to co-creating healthcare systems. The systematic Design Research Methodology (DRM) by Blessing and Chakrabarti (2009) was selected to address this aim. DRM is a suitable and rigorous framework with which to undertake empirical research. DRM has been widely adopted to develop, validate and introduce design supports (approaches, tools and methods, among others) (Eckert et al., 2003; Marxen & Albers, 2012). DRM has been proven to provide rigour to Design research; it is compatible with a Research through Design (RtD) approach (Godin & Zahedi, 2014) and has been adapted to embrace broader applied research agendas (Eckert et al., 2003) in complex systems (Hassannezhad et al., 2019).

DRM defines four stages for the research process in which a 'design support' is developed. A design support can have a tool, method or approach, among others. Depending upon the existing knowledge and how much is known of the phenomena, fewer stages could be required. DRM is flexible enough to incorporate different methods and facilitate iterative cycles of research. This paper presents the findings related to stages 2 and 3 of DRM (Figure 1). The following sections are focused on the five steps (task clarification, conceptualisation, elaboration, realisation, and evaluation) for developing the design support.

Figure 1 Overview of the DRM conducted to develop the holistic outcome-based approach.

3.1 Step one: task clarification

The design support of this study has the purpose of assisting healthcare stakeholders to co-create complex systems based on a holistic understanding of multiple healthcare outcomes. For this purpose, the holistic outcomes should include a variety of meaningful outcomes for different stakeholders at different levels; a mix of objective/subjective, self-reported, anecdotal and quantitative/qualitative is ideal.

During the research clarification stage (outside the scope of this paper), an initial list of outcomes (Table 1) was defined following a comprehensive literature review process (Arksey & O'Malley, 2005). The literature review was conducted by consulting three databases (Scopus, PubMed, and Science Direct) and three design journals (Design journal, Design Studies and International Journal of Design). Four original keywords and synonyms/variables were employed. Keyword 1: Healthcare (Healthcare, "health-care", "health care", health, {health management}, "good condition", healthiness, wellness, wellbeing, "well-being", wellbeing); keyword 2: Outcome (Outcome, "health metric*", "health effect", "health measure*"); keyword 3: long-term ("long-term", "chronic care", lifelong, "long future"; and keyword 4: chronic care ("Chronic condition" "chronic illness"). Based on the title and abstract, papers were selected for complete review. The inclusion criteria were met when studies explicitly listed outcomes, offered a conceptualisation/operationalisation of the outcomes, and were written in English. Grey literature was included as per recommendation. Outcomes were extracted from the selected studies until saturation was achieved (Saunders et al., 2018). Then, the list of outcomes was revised and clustered by the first author following a summative content analysis process (Hsieh & Shannon, 2005). Finally, the list was verified and refined by the rest of the authors.

Table 1 List of outcomes.

Category	* The initial list of outcomes (Use 1- participatory)	Additions (Use 2-part.)	Current list (Use 3 one-to-one)
Psychosocial	Wellbeing, perceive-sickness, quality of life, satisfaction, crisis burden, social functioning, symptom fears, condition distress, happiness.	Dignity, Anxiety	Wellbeing, quality of life, fear of crisis, social functioning, fear of complications, condition distress, perceived health status, the economic burden of treatment, happiness, dignity and anxiety.
Behavioural	Self-efficacy, physical functioning, healthy diet, health literacy, physical activity, medical adherence, self-care activities, healthy lifestyle.	Personal resilience, independence, home care, independence	Self-care, physical functioning, health literacy, physical activity, medical adherence to treatment, healthy lifestyle, personal resilience, independence, home care and self-monitoring.
Comorbidities	Functional status, fatigue, depression, anxiety, fear of complications, cognitive functioning, survival.	Mental health, heart disease	Functional status, fatigue, depression, cognitive functioning, survival, sickness, mental health, long-term complications, memory problems.
Biometrics	Weight, blood pressure, cholesterol and others depending on the specific clinical condition, such as sugar levels, temperature, heart rate, among others.	Pain, work productivity, fatigue	Weight, blood pressure, cholesterol, pain, work productivity, and others depending on the specific clinical condition.
Quality of care (known as quality and cost in use 1)	Quality of care, health benefits, trust in the physician, satisfaction with treatment, physician cultural competency, time of discharge, safety attitudes (safety climate, teamwork, perception of facilities)	Integrated services, length of stay, personalised care plans	Quality of care, trust in the physician, patient satisfaction, length of stay, safety culture, adherence to clinical guidelines, personalised care plans and integrated working.
Institutional (known as quality and cost in use 1)	Cost, mortality, patients increase, emergency admissions, medical resource use, survival. Adherence to long-term therapies, refill adherence, hospitalisation.	Risks, admissions, attend appointment, money by patient, use of community services.	Healthcare cost, hospitalisation, access to care, attend appointments, money by patient, readmissions, crisis, use of community services, financial barriers.

*Colour code assigned to the category

Outcomes were considered equally important. However, their relevance was granted after the group discussion and researcher reflexivity of the results. Table 1 shows the evolution of the outcomes during the development of this approach.

3.2 Step two: conceptualisation

This step aims to define the functions of the design support. Four main functions were defined: providing a shared language; identifying disagreement; developing a balanced understanding; and making holistic decisions.

- Providing a shared language: the design support should help to build a shared language among the stakeholders. This means explicitly establishing what the outcomes mean in different contexts.
- Identifying disagreement: the design support helps stakeholders to advocate for their outcomes and concerns despite disagreements with other participants. A deep understanding of different perspectives is the goal of this function.
- Developing a balanced understanding: the design support acknowledges the diversity of critical outcomes and how a common path for action may emerge from the result of interrelated outcomes. This approach does not look for a consensus; instead, it aims to build a shared and balanced understanding of outcomes.
- Making holistic decisions: the design support helps to make decisions based on a whole-system judgement. This function recognises that outcomes are the result of complex interactions. Therefore, all the possibilities, interdependencies and unintended consequences of outcomes need to be explicitly communicated to inform decisions (Paina & Peters, 2012).

It is expected that the design support will take the role of a dialectical device, to assist participants when discussing the meaning of outcomes and negotiating trade-offs. These functions should cultivate ongoing sense-making about outcome interrelationships and support the collaborative system development.

3.3 Steps three and four: elaboration and realisation

The elaboration step aims to identify the means to develop the functions. The realisation step seeks to build those means. Therefore, these steps are presented together to communicate the means better.

A participatory open mapping strategy was selected to gather a complex understanding of outcomes from multiple stakeholders. Mapping strategies refer to a graphical way of modelling how systems are perceived. A designerly approach to mapping aims to create an open space to generate visions towards design action and intervention (Sevaldson, 2013). Mapping strategies provide flexibility for the participants to construct their configuration of the outcome interrelationships. However, outcome representations assist participants to focus their mapping on the same systems attribute. This bespoke mapping process is called

outcome-based mapping.

In this approach, the output of the mapping process is called outcome-based system visualisations. These visualisations act as the primary device for documenting discussions and data collection. System visualisations have been recognised in the literature as a suitable strategy to help participants understand complex systems. Systems visualisations have been a common strategy in systems thinking methods to address the discussion of complex topics (Comi et al., 2014; Crilly et al., 2006). Also, systems visualisations have facilitated sensemaking from interdisciplinary perspectives (Holden et al., 2013; Peter & Bowes, 2016; Read et al., 2015).

Different representations of outcomes support the functions of the approach. Outcome cards (Figure 2) were created to increase the health literacy of the participants, to facilitate the group discussions, and to test strategies like “outcomes champions”. The cards consisted of two-sided 105x148 mm rectangles. On the front: the name of the outcome; on the back: a neutral description of the outcome, monitoring tools and the frequency of the monitoring. A feedback space was included to gather contributions from the participants.

Also, the representations of outcomes took the form of tokens and stickers (Figure 3). These elements encourage participants to interact, move and integrate the outcomes on different surfaces, such as magnetic boards and paper.

Figure 2 Example of an outcome card (front and back).

Figure 3 Example of means and materials: A) outcome stickers and B) outcome tokens.

3.4 Step five: evaluation

This step aims to evaluate the completeness and consistency of the approach (Blessing & Chakrabarti, 2009, p 80). This is an iterative step that takes place throughout the prescriptive study stage that helps to improve the approach. This step is part of the development of the support, and it should not be considered its final assessment.

Two cases were conducted for the evaluation step. The first case describes the use of the design support in participatory sessions and has already been published (Landa-Avila et al., 2018). The second case is a one-to-one implementation with patients and healthcare providers. A summary of both cases is presented in Table 2.

A non-probabilistic convenience sample was implemented to recruit participants to the participatory sessions. Twenty-five spaces for the participatory session were advertised at an international Design conference (DRS2018). Information about the session was published on the conference website to gain the interest of the target participants. Twenty-three design practitioners/researchers attended the session. Teams were created randomly, allocating four or five participants to each. For the second participatory session, human factor students of a master's degree programme in the UK were reached to participate in the session.

Table 2 Cases performed as part of the evaluation step.

	Participatory sessions		One-to-one sessions	
Participants	23 design practitioners and researchers.	10 human factor postgraduate students	10 patients with chronic conditions.	11 healthcare providers.
Sampling	Non-probabilistic sample.			
	Convenience	Convenience	Purposive	Purposive/Snowball
	International Design Conference			
Process	Figure 4a		Figure 4b	

Materials	Outcome cards Outcome stickers A0 blank paper Feedback forms	Outcome cards Stakeholder cards Outcome stickers A0 blank paper Means-ends template Feedback forms	Outcome tokens Blank tokens 40x40cm magnetic board Visualisation examples
Outputs	23 individual outcome-based visualisations 5 team outcome-based visualisations (Figure 5a) 5 narratives of the visualisations Researcher observations Reflectional memos	2 outcome-based system visualisations 2 means-ends structures 2 narratives of the visualisations	21 individual outcome-based visualisations (Figure 5b) 21 transcripts of the whole session.
Data analysis for system visualisations	Frequencies of outcomes included. Identification of dominant visual structure. Frequencies of group labels. Visual frequencies of graphic patterns. (Table 3)		Network analysis using Gephi software (Figure 6). Criteria for the network analysis: Each outcome is a node. Each link is an undirected edge with a weight of 2. Each arrow is a directed edge with a weight of 2. Outcomes within a group are undirected edge with a weight of 1.
Data analysis for transcripts	Open thematic analysis following an inductive and critical realist perspective. nVivo software for thematic analysis.		Deductive content analysis. Unconstrained matrix with categories such as purpose, goal, outcome definition, outcomes (from the network), values, system awareness, system tools, follow-up process and usability.
Communication of results (visualisations)	Table with graphic structures Percentage of outcomes used.		2 outcome-based network visualisations, one for patients and one for providers. 1 visualisation that compares key outcomes between patients and providers.
Communication of results (transcripts)	Themes and comments from participants.		Themes with comments from participants.

Participants of the individual sessions were recruited using a purposive sample to ensure representativity. The patient group was invited through social media and posters in community centres and schools. After contact, the inclusion criteria assessment helped to decide the inclusion of the participants. The providers' group was invited to participate via email. Public profiles of healthcare websites (leicestercityccg.nhs.uk/, nottinghamcity.nhs.uk/, bettercareleicester.nhs.uk/) were scanned to create a list of potential participants. Criteria included having experience in coordinating an integrated healthcare project and being involved in the engagement process. Previous participants referred some participants to this group. The patient group included ten people living with conditions such as: (n=2) diabetes, and (n=1 for each of the following) fibromyalgia, postural orthostatic tachycardia syndrome, leukaemia, psoriasis, sarcoidosis, polycystic kidney disease, rosacea, and myotonic dystrophy. Age range was from 24 to 89 (average of 51.6). The providers' group included (n=6) senior managers, (n=2) commissioners and (n=3) local authorities.

The mapping processes were adapted to facilitate an open mapping strategy (Figure 4). Outcomes were presented during the introduction of the approach. Individual visualisations were implemented in participatory sessions to ensure that all participants' voices were included and to foster confidence in the mapping. Narratives of the visualisations were essential to clarify the visualisations and support their analysis.

Figure 4 Processes followed during a) participatory sessions and b) one-to-one sessions.

4. Results and findings from the evaluation step

Results and findings from the evaluation step are presented in three sections. The first section is about the outcome-based mapping; then, communication outcomes interrelationships are presented; and finally, the analysis of the narratives.

4.1 Outcome-based mapping

The output from the mapping sessions consisted of outcome-based system visualisations (Figure 5). These system visualisations demonstrate how outcome-based mapping can be a

consistent mean to discuss and collect outcome interrelationships.

Figure 5 Output from a) participatory sessions and b) one-to-one sessions.

The outcome-based visualisations also documented how participants built and adapted their outcome priorities. When participants created different arrangements and allocations of outcomes, they were shaping and negotiating their decisions.

Participants expressed that outcome-based mapping offered enough flexibility to express complex needs. Patients and providers engaged and performed well with the activity, even if they did not receive/have graphic training. Surprisingly, designers demonstrated confusion when the activity was explained. Designers commented that clearer and narrower instructions were needed. Some designers proposed to frame the activity inside a problem-solving exercise.

4.2 Communication of outcome interrelationships

Table 3 shows what percentage of outcome cards was used by each group during the participatory sessions with designers. This table illustrates the first analysis proposal for the outcome-based visualisations and is aimed to identified the most integrated outcomes into the system visualisations. Also, the outcome categories analysis aimed to reflect how participants made sense of outcomes and assigned their labels to the groups.

Table 3 Analysis of team visualisations from participatory sessions with designers.

Group	Outcomes categories	1. Quality and cost	2. Comorbidities	3. Clinical	4. Behavioural	5. Psychosocial
A	Patient and non-patient Objective and subjective	100%	100%	100%	100%	100%
B	Disease, patient and healthcare system	100%	100%	100%	100%	100%
C	No categories created	66%	14%	50%	83%	75%
D	Pre-diabetes, diagnosis and treatment	50%	100%	83%	100%	100%
E	Out of control, in control and monitored	83%	86%	100%	100%	100%
Overall percentages		80%	80%	87%	97%	95%

Due to the descriptive scope of the analysis presented in Table 3, a different analysis was conducted for the one-to-one sessions. The network analysis allowed the synthesis of the individual visualisations into two main visualisations (Figure 6). Network analysis is the process by which to model systems using two essential elements such as nodes and links (Havlin et al., 2012). Studies have used network analysis in healthcare systems for different and new purposes (Benhiba et al., 2017), such as the analysis of pathways (Kohler & Ercole, 2020). These new studies have assigned to different system elements the role of nodes and links. This research considered each outcome as a node, and the links were created based on participant structures (see Table 2 for details). Gephi software (Bastian et al., 2009) was used to perform the network analysis.

In this study, network analysis synthesises outcome-based system visualisations without oversimplifying the richness of the data collection. The two outcome-based network visualisations enable the communication of outcomes as interrelated elements. Also, network analysis supports the recognition of critical outcomes by identifying measures such as degree (outcomes with direct influence on others), closeness (outcome closest to all outcomes), and betweenness centrality (outcomes that act as a bridge and connect distant outcomes).

Figure 6 The two outcome-based system visualisations from the one-to-one sessions.

In this case, patients prioritised outcomes such as resilience, self-monitoring and anxiety; whilst providers prioritised integrated working, self-care and dignity. Both groups agreed about the importance of wellbeing and quality of life. Nevertheless, the network analysis provided new categories of outcomes (communities). The colour code in Figure 6 shows how outcomes grouped differently from Table 1. Therefore, network analysis is envisioned as a suitable analysis of the holistic outcome-based visualisation approach. Network analysis

helps to maintain a powerful graphic representation that communicates the complex interrelations among outcomes. Also, the final system visualisations guided the content analysis of the interviews.

4.3 Analysis of narratives

Three main themes emerged from the narratives of the participatory sessions (Table 4).

Table 4 Thematic analysis from participatory sessions.

Theme	Comments from participants
How should the outcomes be used?	Outcomes should be continuously monitored rather than discussed once upfront.
	Psychosocial outcomes should be considered as long-term.
	Health status, happiness, cost and efficiencies were the most mentioned outcomes.
What did graphics represent?	A circle was used to represent a continuous and organic process.
	Lines were used to segregate outcomes.
	Timelines were considered easy to use, but unhelpful in communicating complexity.
How can visualisations be used in practice?	Graphics should look messy to represent complexity.
	Visualisations are a great and simple tool (for designers) to identify correlations and improvement areas.
	Visualisations can help to solve conflicts between patients and providers.

A content analysis was conducted following a deductive approach for the one-to-one sessions (Elo & Kyngäs, 2008). Four main categories emerged (Table 5).

Table 5 Categories which emerged from one-to-one sessions

Category	Insights from participants
Outcomes to reconfigure systems comprehensively.	Useful to monitor what is shifting or constant.
	Useful to assess that our (providers') outcomes meet the patient's needs.
Challenge assumptions and trigger <i>conflict</i> -based conversations.	Useful to identify discrepancies in outcome priorities and reflect about what (and why) it means that.
	Useful to bring conflicting/hard-to-address outcomes and mitigate the vandalisation of data.
Systems thinking literacy.	We need to identify connections and look at the whole process, rather than pieces of service.
	To see how things connect and can cause others is useful to evaluate my decisions.

Usability –	Potential misinterpretation if the people did not draw the diagram.
Prioritisation.	It is harder to choose a priority once we visualise the connections.

5. Discussion of findings

This paper describes the development process of a holistic outcome-based approach to understanding multiple outcomes for co-designing healthcare systems. Findings from this development process show how outcome-based mapping can build mutual understanding and assist discussion amongst different stakeholders. The network analysis is a promising structured graphic analysis that helps to identify critical outcomes and spot agreements and disagreements amongst different stakeholders. This understanding can support negotiation of conflict priorities to facilitate the (re)design of healthcare systems.

5.1 Strengths and considerations for the holistic outcome-based approach

THE ROLE OF OUTCOMES

Outcomes are the key element of this approach; nonetheless, outcomes are not considered the most critical element of healthcare systems. Outcomes need to be understood as key drivers in creating a shared understanding of other people's meaningful needs. Patients and providers understood this role for outcomes more clearly during the sessions. Both sets of participants were confident in selecting their own needs and in using outcome interactions to represent their vision of the system. Also, participants recognised that other stakeholders might prioritise outcomes differently and, therefore, that certain key priorities within healthcare systems require a deeper understanding of how multiple outcomes interact.

This practical approach towards outcomes can help to expand system thinking models such as SEIPS and CWA. SEIPS 2.0 categorises outcomes as un/anticipated, short/long term, and intermittent or constant (Holden et al., 2013). Although this categorisation seems a sensible proposal, participants of the above cases created different categories to work with outcomes. Thus, open outcome-based strategies could be more beneficial to '(re)develop' systems. CWA has exposed how outcomes keep a relationship with other elements of the system, but it is more prescriptive about how to collect those relationships. During the mapping sessions above, participants organically created relationships among outcomes and diversity of system elements. The outcome-based approach provides a more naturalistic/logical way in which information can be collated. Nevertheless, the CWA structure could be useful for researchers to conduct further outcome analysis.

Surprisingly, designers were more cautious and struggled to use outcomes for creating a complex representation of systems. Outcomes are less represented in design theory; therefore, less 'practical experience' was expected from the design community. Thus, an outcome-based approach should be explicit in conceptualising the role of outcomes for design practitioners. A primary concern is that outcome-based system visualisations may be understood as the 'expected result' from a design intervention. This approach does

not attempt to be a foresight method, but rather a dialogical device for sense-making and reflection towards a systems thinking oriented process of change. Then, the understanding of multiple outcomes can be embedded in the design development process as a dynamic element supporting new/desired skills of designers to interpret a complex system situation (Dorst, 2019).

Nevertheless, these findings are not conclusive in defining whether this approach can be relevant to all levels of healthcare systems. These cases were contextualised within chronic care services (Meso level) in an attempt to include a variety of stakeholders and societal structures. Senior managers and patients coped well using this approach in this level of the system. Participants mentioned potential uses in one-to-one counselling, as well as in the development of pathways. However, further research could explore different scenarios of use to define whether this can be used in micro as well as macro contexts.

Lastly, the outcome list provided (Table 1) should not be considered as fixed. Although the list was a product of reviews and practical applications, different contexts, times and situations could require adaptations. During the one-to-one sessions, patients and providers added 'new outcomes' (e.g. mobility, civility) that probably fall outside of a traditional/narrower definition of outcome. This agrees with literature urging the differentiation of related concepts such as outcomes, needs, goals and values; although, it might be the case that all applications are correct (Naikar et al., 2005, p 25). Due to the exploratory scope of this study, all 'new outcomes' were included in the study analysis; however, this approach should define/justify the degree of flexibility regarding the definition of outcomes. Also, this outcome-based approach can benefit from integrating values, as has been done in PPC (Naik et al., 2018).

PEDAGOGY OF SYSTEMS THINKING

There is a small, but growing, literature base regarding how we teach/introduce systems thinking approaches. The findings presented agree with the valuable use of visual strategies to understand/work in complex systems (Jones & Bowes, 2017; Jun, Kim, & Lee, 2011). All participants increased their systems thinking jargon and awareness. It will be an ethical responsibility of the outcome-based approach to offer a formal introduction to systems thinking, in order to facilitate engagement with the approach in the long-term. Also, this formal introduction could diminish the risk of misapplying the complex system paradigm. Concepts such as (new) systems, problem, intervention and process of change can conflict with some design conventions.

The role of stakeholders as co-creators of systems demands more study. Whilst designers showed confidence in performing a 'visual' strategy, patients and providers could recall experiences and build richer maps even without graphic training. This posed questions about the concept of a designer of complex systems. Systemic design literature has provided knowledge about designers as systems thinkers/facilitators and how stakeholders become the system designers (Jones, 2018). Still, these new roles need to be enforced/positioned by new system thinking approaches.

NEGOTIATION

This approach triggered ‘conflict-based’ discussions that can be a powerful strategy to build meaningful relationships between stakeholders. Conflicts do not necessarily imply negative results or power fights. Conflict-based discussions could challenge assumptions and increase the understanding of what others perceive as important. Participants manifested that outcome-based visualisations can be a suitable way to visualise discrepancies and think critically about priorities. Then, participants can make a shared decision based on a ‘more comprehensive vision’ of the system. This agrees with Paina and Peters (2012) who identified that a comprehensive visualisation of interdependencies and unintended consequences lead to making better decisions.

Despite the benefits, healthcare providers were the least keen to recommended mixing stakeholders from different groups to build the system visualisations. Instead, providers proposed to gather visualisations from different groups and compare them later. Although such an isolated application of the method would not provoke as a rich a discussion, it is not entirely discarded as a strategy to cope with resistance to the use of this approach in participatory settings.

5.2 Interdisciplinarity, challenges for design, healthcare and systems thinking

There are challenges to expanding the synergy between systems thinking and design into developing healthcare systems. Healthcare providers manifested that more practical resources are needed to hold meaningful encounters with different stakeholders before starting an intervention. This ‘starting point’ goes beyond initial steps in well-known design models such as the double diamond (Design Council, 2019) or the fuzzy front-end (Sanders & Stappers, 2008). This ‘starting point’ is an ongoing need to comprehend healthcare systems. Systems thinking has put more emphasis on ‘grasping systems’ as a constant learning action, rather than just a practical acute application (Swanson et al., 2012). Hence, design has the challenge and opportunity to reconfigure its process as a cyclical learning intervention.

The experiences of using the outcome-based approach with designers highlighted the prevalent paradigm of problem-solving. Design should address ill-defined circumstances in healthcare that are not typically understood as problems. Healthcare systems face dynamic states over time looking for improvements/changes (Braithwaite et al., 2018). A whole picture of the system situation is needed if designers aim to intervene in the system (Ulrich, 1988) and tackle the problem situation (Checkland, 2000). Then, designers should be consciously aware that defining a problem should be translated into defining/understanding complex situations and wicked problems when working in systems. As pointed out by Jones (2014), systems thinking and design need to renegotiate how they formulate ‘problems’, otherwise their collaboration will be superficial. Therefore, designers should have the ability to repeatedly frame complex problems instead of solving problems (Dorst, 2019). Also, designers need to be aware that complex systems are continuously/dynamically redesigned. Hence, any attempt to design a completely new system is ‘not possible’.

These results support the need for systems thinking to clarify its meaning and concepts within the healthcare sector (Plack et al., 2018; Rusoja et al., 2018). By the end of the sessions, participants were more aware of complex systems attributes, such as interconnection and feedback loops. However, training participants in systems thinking was beyond the scope of the approach. A robust bespoke approach for healthcare could offer support to introduce system thinking to participants; nevertheless, the recognised lack of consistency of the “system thinking” concept makes this task more challenging.

Finally, healthcare evaluation/monitoring needs to expand its sources of data/evidence. Patients demand more comprehensive monitoring; similarly, providers want to increase the diversity of evidence which inform decisions. In the cases described in this paper, it was encouraging to see how positively the healthcare providers reacted to how the data was collected and presented. Therefore, designerly ways of constructing evidence with outcome-based visualisations should be explored further.

5.3 Limitations and future work

First, the findings presented correspond only to stages 2 and 3 of the DRM. Stage 4 will expand the knowledge about the practical implications of this approach in design practice, and to what extent it can inform other well-known design methods. Furthermore, it is recognised that larger action-based applications are needed to assess the impact of this approach. In addition, this study has been limited by the opportunities to implement the method with heterogeneous groups, as the participatory sessions were conducted with participants of similar backgrounds. The participatory sessions have been conducted with participants of similar backgrounds. Although it is recognised that disagreements can arise in this context, further research with heterogeneous groups could explore negotiation in detail. Finally, the role of the facilitator needs to be mitigated. Participants mentioned that the method was easy to understand. However, it should be further reviewed on how this method is conducted by different facilitators.

6. Conclusions

This paper presents the development and application of an outcome-based approach to co-creating healthcare systems. This approach has been used with design practitioners and researchers, patients with chronic conditions, and different healthcare providers such as senior managers and local authorities. The findings recognise that the outcome-based visualisations create a shared understanding of the interrelated outcomes that support the identification of agreements and disagreements for co-(re)designing healthcare systems.

The findings of this paper contribute to reconceptualising and strengthening the value of healthcare outcomes for different stakeholders. Outcomes are an underappreciated element in the design process, and despite having a more critical role in healthcare, there are few deep reflections about them in either area. However, outcomes can help to identify well-rooted disagreements and (re)define a holistic system purpose. This paper acknowledges

that a holistic perspective should include a variety of outcomes, such as: subjective/objective, patient-reported, clinical-experienced, qualitative/quantitative, and anecdotal, from different stakeholders at different levels (from micro to macro). Also, it recognises that related concepts such as values and goals need to be formally integrated/defined in this approach to avoid being misunderstood.

Outcomes can be design drivers, that provide a more holistic vision of the interrelated needs of different stakeholders. Also, this method can support designers in becoming problem framers of ill-defined healthcare situations. Outcomes should be embedded in planning/develop as dynamic/proactive elements. As dynamic elements of the systems, outcomes have complex relationships, interact with other outcomes, and are sometimes unexpected/emergent. Further studies could explore how emergent outcomes can expand how success and failure concepts are employed in healthcare.

These findings can have an impact on the dissemination of complex systems in both design and healthcare. This approach provides new resources for practitioners and providers to engage in complex conversations, build common ground, and contribute to depicting a *whole picture* of healthcare to make shared decisions. Also, this holistic outcome-based approach can expand other well-known systems development frameworks/approaches such as SEIPS and CWA; it also can strengthen systems thinking methods for healthcare design.

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7. References

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