Designing synthesis maps for its stakeholders and its development

Working Paper

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Related Case Studies: Visual knowledge translation for CanIMPACT clinical system and patient cancer journeys by Peter Jones, Designing A Synthesis Map to be used by its stakeholders: What to expect when navigating and shaping Ontario’s Fertility Program by Laura Halleran, Synthesis Maps: Visualizing The Patient Experience by Denise Philpott, and Applying Meaning to Research through Iconography and Visualization by Sonia Tagari
Abstract

Over an eight week term, The ART of the Waiting Game: How to navigate Ontario’s assisted fertility system, synthesis map was designed by three graduate students from OCADU’s Design for Health masters program. The synthesis map theorizes a response to the unmet need of a unified resource for women that contains the information necessary to address their reproductive health and navigate the assisted reproduction system in Ontario, Canada. This exercise, overseen by professors Peter Jones and Cameron Norman, demonstrated systems mapping methods used to communicate patient barriers related to complexity within Ontario’s fertility system. The following case study outlines the synthesis mapping stages: framing the situation, forming stakeholder hierarchy, developing a narrative, creating a visual language, and formally modelling the system and abstracting these models. A summary of learning outcomes, recommendations, and next steps based on the first iteration of synthesis will be provided as a scaffolding for future synthesis map creation.

Purpose Statement

The purpose of this case study is to provide a framework of development and visualization to produce a synthesis map that communicates complex medical journeys to patients, policy makers, and care providers.

Background

Synthesis mapping provides a graphic visualization of a stakeholder’s experience over a period of time as they interact within a systems environment (Howard & Tharon, 2014). Synthesis mapping has been identified as a valuable tool to understand how a system works, the mental models existing within with a system, and the service gaps resulting from system and mental model misalignment (Ackoff & Gharajedaghi, 1996).

Within the healthcare context, synthesis mapping can provide a high-level overview of the care system as a whole, and communicate valuable insight into how a patient’s experiences that system. The ART of the Waiting Game synthesis map is an attempt to demonstrate this, and works to translate clinical stages into a patient, personal journey using images, infographics, hierarchy, colour and key words and phrases that will resonate with the thoughts and feelings of a current or potential patients of the care system.
As healthcare encounters the challenges of rapidly changing populations and increasingly complex patient profiles, it is the authors’ opinions that synthesis mapping can help distill and portray complicated systems in an understandable manner.

**Introduction**

**Selecting a System to Study**

As students in OCAD University’s Design for Health graduate program, the authors were tasked with developing a synthesis map to explore the complexity of a health system. This eventually led to focusing on the system in Ontario that provides female assistive reproductive technology (ART) to women in the province. This task proved to be more difficult than expected however, as there was no single resource that could provide an overall understanding of how this system works, and what it would be like to experience as a patient.

Preliminary research also indicated that there was a need for this understanding, as one in six couples in the province of Ontario struggle with infertility at some point in their lives (Johnston et al., 2009). Statistics Canada also reports that the average age of first-time mothers in Canada has increased to 30 years old. To-date this is the oldest recorded age, condensing their childbearing window into a relatively short time frame as female fertility significantly declines after the age of 35 (Statistics Canada, 2017). Collectively, this reality has created a growing need for ART, as well as an understanding of how to navigate Ontario’s Fertility Program, which regulates these technologies in the province and provides funding and services for people seeking funded fertility assistance (Office of the Premier, 2017). This led the authors to design a synthesis map that would act as a unified resource for women navigating the fertility program in Ontario, which visualized the physical and emotional toll, and material investments women will experience and have to make in order to undergo the most common form of ART, in-vitro fertilization (IVF) (National Center for Chronic Disease Prevention and Health Promotion, 2017).

**Aims of Creating A Synthesis Map**

To act as a unified resource, the authors worked to illustrate the patient perspective alongside a timeline of clinical stages to guide women through sequential steps and to validate and respond to their own experiences and concerns when considering IVF. This approach was taken to also highlight opportunities where patient and organizational needs were misaligned and could be better met. This led to the following objectives:
• Gather information about Ontario’s fertility system relevant to the patient experience
• Use a general snapshot of a patient’s first IVF cycle to visualize system complexity
• Graphically highlight areas of opportunity within a timeline of clinical stages
• Use an authentic patient voice using graphics and first-person narrative

Methods and Outcomes: Stages of Producing A Synthesis Map

The synthesis mapping process used for The ART of the Waiting Game was based on the teachings in OCAD University’s Systems and Communications II class. In this studio setting, systems principles, understanding complexity and operational thinking was practiced using Jamshid Gharajedaghi’s book Systems Thinking, Managing Chaos and Complexity as an educational text. Further clarification was cited from Jones’s et al.’s case study, Visual knowledge translation for CanIMPACT clinical system and patient cancer journeys (Jones, Shakdher, & Singh, 2017). An innovation paper written for another course by the authors on ART also helped to contextualize this technology and to identify a need for a graphic product to communicate useful information about Ontario’s fertility system.

The following will provide framework that was used to produce a synthesis map that will be used as a navigational tool for its primary audience.

I. Framing the Situation in a Meaningful Way

As three women living in Ontario, the authors asked themselves what questions they would have when considering ART. This perspective was strengthened significantly by the non-systematic ethnographic research and informal interviews with prospective IVF patients in Ontario. This insight led to the desire for the map to be a tool designed by women for women, and was visually conveyed through the inclusion of the authors throughout the patient journey. A review of fertility clinic practices combining system map sketching, contributed to producing a timeline between the start and end points - “thinking about conception” to “completion of the first IVF cycle.”

II. Forming Stakeholder Hierarchy

The poster follows IVF patient personas moving through an established timeline of clinical stages and provides a glossary of definitions and fertility clinic directory. Read from top to bottom, the poster is divided into three sections by colour - timeline (blue), policy (red) and a glossary (white). Iconography is
featured throughout to alert the reader of helpful information about cost, funding, time and travel. The synthesis map visual hierarchy can be summarized through the following elements:

**Timeline (Blue)**

The timeline runs through the middle of the poster and depicts treatment chronologically. Patient personas are used to address concerns and questions using thought bubbles.

**Policy (Red)**

Policy and barriers are exhibited in red. In addition, red egg shaped bubbles highlight service gaps within the blue clinical timeline.

**Glossary (White)**

One of the key findings in literature reviews and online ethnography communicated a steep learning curve in fertility terminology and knowledge of clinic locations. The glossary lists key words, abbreviations, acronyms, definitions and clinics in one place

### III. Developing a Narrative

The authors framed the map with common questions seen on IVF.ca through a non-systematic forum scan. Quotes were pulled that reinforced difficult points of the treatment journey to illustrate directly various problems with ART through the words of women who had experienced them. In part, this was to recognize that IVF and ART impacts the lives of real people, of the women in our audience, and to acknowledge their frustrations as valid. ART is more than just a stepwise series of treatments, it is a difficult and often emotional journey rife with information gaps and complex treatment options. The intent was to answer questions that women are asking so that the map potentially could help alleviate some stress caused by a convoluted and complex system.

### IV. Creating a Visual Language

Overall, the goal was to create a written and visual language that would look and sound like two friends chatting about the very personal topic of sex, reproduction, and children. The map is meant to be a friendly, no frills tool that is as all-encompassing as possible for women engaging with the highly siloed ART process and system. That being said, there was a challenge in creating a visual language that was respectful of the weight that can come with ART. Thus, the authors kept it as straightforward as possible. Bright and dynamic vector graphics were chosen of simple geometric forms paired with
straightforward cartoons to represent three women (ourselves). Shapes reminiscent of human gametes -- ova and sperm -- were used to further communicate that ART is entirely tied to reproduction. Several references to time were also used, a key resource in the ART and IVF process. This was purposefully done to communicate the highly complex concepts of the ART journey in as quick, friendly, and accessible a way as possible.

V. Modelling the System & Abstracting the Models

Causal Loop

There are many facets that influence the need for ART and the decision to undergo the procedures. It was believed a causal loop diagram would best display how these forces interact, reinforcing one another to compound the pressures. Importantly, there may not be a balance in this system.

Causal loops are great at showing how different elements of a system interact with one another, but their accessibility to an audience outside the system community is limited. Since causal loops may not readily understood by laypersons, the metaphor of putting “all your eggs in one basket” was used to show the choice that women have to make between lifestyle and biology, with each labeled egg representing a major pressure that shows why women turn to ART. Here the authors wanted to show that when it comes to having a child, women are competing with economic, social and lifestyle factors.

Bathtub Diagram

On the surface, it may seem that ART just required a doctor’s appointment with a few procedures and tests. In reality, there are many different inputs required for an ART treatment. IVF was chosen as an example since it is the most common procedure and used a modified bathtub model to represent the different resources (faucets) that run into the procedure (the tub). The modified version aims to be highly legible for a layperson reading the map. Lost time, costs, and stress are the three drains in a system that does not guarantee pregnancy as an outcome. In this sense, women invest immense amounts of time, energy, and resources into an uncertain future.

A modified bathtub model was used to represent the different resources as the faucets that run into the procedure, the tub. ART requires investment not just of money but of time, physical health, and emotional well-being. Modification was meant to render legible the specialized bathtub diagram, so that a reader would not need expert knowledge to understand the personal inputs into the ART system.
Journey Loop

Beyond showing the medical, time, and money investments, we wanted to show the reality that IVF does not happen as a one-and-done procedure. IVF, in tandem with IUI, occurs in multiple cycles that take time, effort, money, and a large array of emotional strains that accompany hormone shots.

Modified loops, were also used, here called a journey loop, to represent the cyclic, uncertain nature of IVF and ART. ART does not guarantee pregnancy, and often requires multiple treatments. This egg-shaped loop is designed to show that IVF happens in multiples and brings about the physical and emotional burdens listed above it. While a woman might see finally arriving at IVF as a moment of respite during the long patient journey, it is still a strenuous and often stressful experience with an invasive procedure.

The authors wanted to depict with clarity the potential endless loop and repeated input of resources possibly required by ART. Finally receiving treatments like IVF does not mark the end of the journey. It is a stressful, invasive procedure. The authors wanted to show, with this diagram and others, as holistic a view as possible of the inputs, resources, and steps needed for an average single round of a treatment.

### System maps: creation process

Example of the causal loop demonstrating the harsh reality of dependence on reproductive technology and a hybrid journey/bathtub model illustrating patient point-of-view and investment.
Challenges and Limitations

The focus of the synthesis map used as an example in this case study relies upon fertility treatment plans funded by the Canadian government and therefore discludes any non-funded alternative or traditional treatments. There was no direct consultation with current IVF patients or professionals, ideally focus groups or collaboration with fertility clinics and professionals would have been used to inform research focus, confirm research findings as well as provide further qualitative insights. A short time-frame and the new experience of visualizing health systems resulted in generalized citation and superficial online ethnography, leaving opportunities to better decode meaning and pattern of behaviours. An additional challenge is the constant changing of policy surrounding ART in Ontario. Even over the past six months, the Ontario Fertility Website has undergone significant changes.

Learning Outcomes

Overall a lot was learned in this process. First being systems models in their formal form. But also, the process of abstracting these models with a visual language in an attempt to make them meaningful to an intended audience. Furthermore, the authors feel there is potential for synthesis maps to be designed to be used by audiences outside the academic community. The focus here is a healthcare context and how to design a map to be used by patients to navigate clinical stages. But this is by no means a limit, and it is exciting to think of the different audiences and intended uses for which a synthesis can be designed.
Laura Halleran and Sonia Tagari presenting *ART of the Waiting Game* synthesis map (first iteration) for feedback.

### Recommendations

As with all first iterations, the synthesis map created requires further development. *The ART of the Waiting Game* would greatly benefit from the following refinement methods:

- Patient and clinical professional collaboration throughout the next stage of development
- Further investigation into imagery and clinical stages to convey deeper meaning and technical information about treatments
- Apply grounded theory methodology to online ethnography to produce evidence-based categories, themes and patterns
- Considering alternative formats to be in dialogue with changing resources

### Next Steps

The synthesis map is meant to be a tool for women to navigate the twists and turns of the convoluted fertility system in Ontario. Beyond that immediate purpose, the authors see the map being used by policy makers to identify gaps in care that can be patched with policy that supports women who are
journeying through the ART procedures. Based on these insights *The ART of the Waiting Game* synthesis map can be further developed to present a resource for patients by:

- Seeking and establishing partnerships with fertility program patients and clinical professionals
- In-person interviews, documentation of treatment equipment, procedures and storyboarding
- Focus groups to gain user feedback
- Open coding of selected IVF.ca discussion forums for women aged 35+ undergoing fertility treatments

Furthermore, feedback from RSD6 encouraged both user-testing of the map and consideration of different platforms on which to share the information uncovered by our research. User feedback from our primary audience is a key component that could be improved to fortify our map, and making it as accessible as possible to facilitation information dissemination is a significant goal.

**Conclusion**

Infertility is prevalent in Ontario, and has created a need for and reliance on ART. The Ontario Fertility Program has been developed to meet this need, however, currently there is no resource that provides an overview of the system, to help women understand what emotional, physical, and financial investments they will have to make to be a patient. Synthesis maps help to visualize complexity and represent the dynamics and relationships that shape a system through formal models. Through careful framing, developing a stakeholder hierarchy, narrative, and visual language to abstract formal system models, the authors believe synthesis maps can be designed as a tool for a specific audience. In this case, *The ART of the Waiting Game* has been designed to be a navigational tool for women in Ontario considering or undergoing IVF. While the map remains in its first iteration, a pivotal next step is to go through user-testing and gain feedback from women in Ontario’s Fertility Program.
Works cited


