



FROM THEORY TO PRACTICE:  
CREATING A TOOLKIT FOR ENGAGED DESIGN

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From Theory to Practice: Creating a Toolkit for Engaged Design  
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## Abstract

Researchers and designers alike have called for more inclusive and participatory approaches to be used within design. By first exploring the work of researchers designing with older adults living with dementia and expanding to a more robust literature review surrounding inclusion in design, I found that the literature not only suggests that design could benefit from an integration of interdisciplinary knowledge, critical reflection of methods and intentional interaction with users, but also presents theories for doing so. This project condenses four of those theories into key principles, and uses them to present a framework of Engaged Design, a mindset intended to help designers prioritize critical reflection of their processes in order to interact more meaningfully with their users.



# Introduction

## Motivation

This project came out of my desire to be more inclusive in my own design practice. As a student, I often found it challenging to embrace the rules and science of design methods while trying to allow space to invite others into the process in an inclusive fashion, regardless of their background or ability. Following the frameworks of user and human-centered design, the perspectives of intended end-users should be a critical focus throughout the design process [10], [15]. I believe these principles inherently extend to incorporate an inclusive mindset, welcoming the perspectives of all individuals. However, throughout my work, I found myself questioning how inclusive my methods really were; might I be limiting the voices I heard by the approach I used?

Researchers like Gillian Hayes have acknowledged a need for more participatory and inclusive approaches in design as well [1], [12], showing this interest in inclusion isn't simply personal, but critical for the field as a whole.

With these challenges in mind, I set out to explore this question:

**How might we promote the use of more inclusive approaches in design?**



## Related Work

### **Designing with Older Adults Living With Dementia**

There are many researchers who have begun to explore this idea of inclusivity while conducting design work with older adults living with dementia (e.g., see [13], [17], [18], [19], [23]). Dementia is an umbrella term that refers to a number of different diseases that affect the brain. Because of this, dementia can manifest through a variety of symptoms including memory loss, speech impairment, degradation of executive functioning or affected motor functioning [26].

Since inclusive design methods should welcome individuals with varying strengths, abilities and ways of experiencing the world [16], [21], older adults living with dementia are a great population to work with to better understand the challenges and potential that are presented by current design methods.

#### **Challenges**

Research around design with older adults living with dementia often results in an acknowledgment of challenges within this process [14]. Lazar et al recognize that people living with dementia may have complex communication needs, experiencing challenges in producing or processing speech. This can be a barrier to engaging with this population as designers so often rely on verbal communication to learn about and work alongside their users, and may result in designers engaging with proxies (e.g. caregivers, family members) rather than the person themselves [17], [18].

As designers, we often present people with sketches, ideas or low-fidelity prototypes and speak about them in their final, polished form. This translation may not be so clear for older adults living with dementia because the ability to think abstractly may be affected by the disease [20].

Additionally, researchers have recognized that simply participating in a design session may be a stressor for older adults living with dementia as this experience has the potential to cause unnecessary frustration or confusion due to the expectations and norms (e.g. following a strict schedule, answering many questions) associated with these sessions [14].

## **New Approaches**

In response to many of these challenges, researchers have begun experimenting with new approaches and ways to adapt design methods in an attempt to be more inclusive to this population. For example, researchers are considering ways in which gesture and movement might be used to supplement verbal communication during inquiry [18], [22].

Other researchers have explored the idea of implementing a more relational approach to design by engaging with older adults living with dementia in an informal setting over a long period of time rather than only interacting during sessions like design workshops or focus groups [13].

Researchers are also starting to look to other disciplines like art and art therapy as a way of engaging with users [18]. Wallace et al combined the method of cultural probes [9] with artistic prompts as a way to understand their users and identify a need to address through design [25].

## **Topics Related to Inclusion**

Much of the research around designing with older adults living with dementia, is posed in conversation with other topics related to inclusion. This work has led to a recognition and questioning of the power structures and inherent hierarchies that exist between designer and user [17], [24]. Researchers have explored issues around identity, representation, and decision making that come up in design [7], [23]. Additionally, some researchers are playing with the idea of combining the traditionally distinct phases of inquiry, creation and dissemination in order to allow for inclusion at each step [5], [25].

## **Interdisciplinary HCI Theories**

As human-computer interaction (HCI) researchers respond to design's transition into bigger sociocultural oriented spaces [11], they are taking on the many facets of inclusion and presenting arguments for integrating theory from other fields into design (e.g., see [3], [7], [8], [17]).

In *Social Justice Oriented Design*, Dombrowski et al argue that incorporating ideas from social justice theory will help to support "polyvocal participation". The authors also recommend designers move away from their traditional role as a "neutral party" and use active reflection to consider how their own identities and values play a role in their designs and methods [8]. Shaowen Bardzell suggests the HCI community could work to adopt commitments of feminist theory including advocacy and pluralism in order to welcome and support a broader range of users [3].

Bennet & Rosner drew from both disability studies and feminist theory to critique current design methods meant to build empathy. They argue that a more intentional commitment to empathy (rather than an empty assumption of empathy) may help to create stronger connections between designers and their users [4]. Similarly, Bannon et al called for a reimagining of participatory design (PD), recognizing that PD must work to evolve alongside the field of design as a whole [2].



# Methods

## Identifying a Gap

After completing a thorough literature review and learning about how researchers are addressing inclusion in design, I recognized **the literature supports that design could benefit from an integration of 1) interdisciplinary knowledge, 2) critical reflection of methods and 3) intentional interaction with users** and presents theories for doing so.

The academic community has constructed a robust basis of evidence for ways to promote inclusive design, which the design community could greatly benefit from. However, the design community could even further benefit from a simplified and concrete translation of these theories in order to more easily integrate them into practice. The remainder of this paper will walk through the process of summarizing these complex theories in order to communicate them out to the design community.

## Summarizing Theory

Four papers were selected that represent a comprehensive yet diverse selection of interdisciplinary HCI theories supporting inclusive practices:

- Social Justice oriented Design: Outlining Key Design Strategies and Commitments [8]
- Feminist HCI: Taking Stock and Outlining an Agenda for Design [3]
- The Promise of Empathy: Design, Disability, and Knowing the "Other" [4]
- Reimagining Participatory Design [2]

In each of these papers, the authors present core commitments, tenets or principles associated with their presented theories (see table on following page).



## Overview of Theories Summarized

Paper/Theory	Core Principles
<p><b>Social Justice Oriented Design</b> (Dombrowski et al, 2016)</p>	<ul style="list-style-type: none"> <li>• Design for Transformation</li> <li>• Design for Recognition</li> <li>• Design for Reciprocity</li> <li>• Design for Enablement</li> <li>• Design for Distribution</li> <li>• Design for Accountability</li> <li>• Commitment to Conflict</li> <li>• Commitment to Reflexivity</li> <li>• Commitment to Ethics and Politics</li> </ul>
<p><b>Feminist HCI</b> (Bardzell, 2010)</p>	<ul style="list-style-type: none"> <li>• Pluralism</li> <li>• Participation</li> <li>• Advocacy</li> <li>• Ecology</li> <li>• Embodiment</li> <li>• Self-disclosure</li> </ul>
<p><b>Commitments to Empathy</b> from The Promise of Empathy (Bennett &amp; Rosner, 2019)</p>	<ul style="list-style-type: none"> <li>• Rather than seek to represent another's experience, we seek partnerships in imagining the design encounter</li> <li>• Rather than achieve an understanding, we seek a process of ongoing attunement</li> <li>• Rather than attempt symmetry, we recognize and work with asymmetry</li> </ul>
<p><b>Reimagining Participatory Design</b> (Bannon, 2018)</p>	<ul style="list-style-type: none"> <li>• Public participation</li> <li>• Sensitivity to social conflict</li> <li>• Shared trust</li> <li>• Mutual learning</li> <li>• Security</li> <li>• Fairness</li> </ul>

These core ideas acted as the data for our summary analysis. Some of the more complex ideas were separated out into parts, for example, *design for transformation* was broken up into 1) *recognize importance of fluidity and malleability* and 2) *recognize the long term nature of your impact*. Additionally, a few key concepts from earlier in the literature review were incorporated. This resulted in 38 total pieces of data.

I used an affinity diagram [6] to cluster this data and derive overarching themes, which were used to condense these complex theories into seven actionable principles:

- Critically Reflect on Your Own Work
- Transparency is Key
- Prepare to Adapt
- Seek Partners, Not Participants
- Recognize Diverse Perspectives
- Consider Your Full Impact
- Think Long Term

[See Appendix for full breakdown of data that comprised each principle cluster]

## Communicating

These seven principles act as clear and digestible ways for designers to comprehend the full complexity of the interdisciplinary HCI theories behind them. In order to easily refer to these ideas and the inclusive goals behind them, I decided to call them ***Tactics for Engaged Design***. In this case, “Engaged Design” was chosen as these principles are intended to help designers engage with both their methods and their users by prioritizing critical reflection of their processes in order to interact more meaningfully with their users.

To easily share these ideas out with the design community, I chose to create a toolkit. Toolkits are small manuals often used to help designers learn new skills, frameworks or methods. Design toolkits often consist of informational sections and activities for practice [15], [21]. This format will allow me to present an overview of Engaged Design as well as a deeper dive into each principle.

The outcomes section that follows provides an outline of how each principle might be presented within a manual.



# Outcomes

## Critically Reflect on Your Own Work

Critical reflection should be built into the design process - not only at the end of a project, but before we even get started. It's important to identify your own interests, resources, strengths and goals so that you can adequately communicate these to potential collaborators and partners.

As designers, we are often tied to outside clients, funding, missions and timelines, some of which may not allow for flexibility. Identifying these constraints early on will allow for full transparency around needs and expectations when work with stakeholders begins.

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### What Do You Bring to the Table?

30 minutes

Take some time to map out your experience, expertise and network. If you were approaching a potential collaborator, what would you want to share with them about how you would approach a project?

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### Dream Project

45 minutes

Identify one of your dream projects:

- What topic would you address?
- What would you bring to this project?
- Who would you want to partner with?
- What methods would you use?
- What would you get out of this project?
- Why is this important to you?

Use this activity to practice articulating your interests, goals and expectations for future work. Take time to plan out a full design process to tackle this project, how could you integrate the principles of engaged design throughout this project?

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## Identify your values

Design isn't a field that people get pushed into accidentally - we are all here for a reason. What brought you to design? Identifying what you value about your work can help you engage more meaningfully with your processes.

## Transparency is Key

Transparency is crucial for laying the groundwork for engaged design. Building transparency into your process doesn't require drastic changes, it simply requires you to be up front about your intentions, goals and expectations.

Clear communication is important whether you're working with a one-time participant or a long-term collaborator. Designers should be intentional about fostering a shared sense of trust among all partners.

Don't let formality get in the way of the more human qualities of design - it's okay to let a participant know you're trying out a new protocol or method - just be honest!

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### Reflect on Your Transparency

30 minutes

Think about the last time you were trying to better understand your target users:

- What methods did you use?
- What did you get out of this process?
- What did you tell your target users about this process?

Write up a plan for how you could build more transparency into this process in the future.

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### Transparency in Design Solutions

30-60 minutes

Take 3 minutes to write down as many forms that a design solution can take as you can think of (for example: poster campaign, website, conference event, etc)

For each method, identify how you could build in transparency or help the design solution to self-disclose its intentions on its users.

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#### A note about agendas:

We all have agendas and that is okay! It's when we try to hide our agendas that problems arise. Make your agenda explicit by sharing your specific interests, needs and expectations with potential collaborators.

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## Prepare to Adapt

Being able to adapt your goals and methods can help you to be more in-tune with your work. Adaptation is important in both the short-term and the long-term. Don't be afraid to go off script or change your approach for a particular session in order to better support the strengths of your participant(s).

Recognize that some of our methods may be limiting who we reach - if we rely heavily on self report, verbal communication, or abstract thinking, we may be cutting ourselves off from the perspectives of those who are not fully able or willing to participate in these approaches. Embrace the fluidity of the design process by allowing for many different ways to engage.

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### Adapt!

45 minutes

Make a list of design methods you use most frequently (aim for 5), as well as the main goal(s) of each method. For each method on the list, choose a constraint below and brainstorm how you would accomplish those same goals.

- You cannot speak to your participant(s)
- You have to do this in the dark
- You and your participant(s) are running an obstacle course
- You have noise canceling headphones on
- You and your participants must speak in rhyme
- Come up with more constraints as you go!

Use your responses to serve as inspiration for how you might offer different forms of interaction in your future projects!

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### Know your methods so you can break them

Expect the unexpected and prepare yourself ahead of time. Be comfortable enough with the goals and approach of your methods so you can adapt as needed without losing the spirit of your methods.

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## Seek Partners, Not Participants

The interaction that occurs within the design process is often heavily based in hierarchy. Even with the best of intentions, designers hold power over what questions get asked and what information is deemed important. User involvement is often a one-way exchange, with user participants providing data to designers and not receiving much in return. If we can shift our view of “participants” to a view of “partners” we may be able to shift the power dynamic as well.

By lifting our users to the same esteem as a researcher or consultant and acknowledging that people are in fact experts of their own experiences, we can build a stronger rapport with those we are designing for.

### Collaboration for Collective Knowledge

If we invite users to the table to act as partners, we can begin to cultivate an attitude of trust and appreciation. With these partnerships, we can expand our shared knowledge base and understanding of the issues at hand.

By including partners in shared decision making and processes like ideating and prototyping, we can cultivate an attitude of trust and appreciation.

### Quality of Engagement

We must not only consider the frequency of interaction but also the quality of engagement. When interacting with partners, does it feel more like conversation or an interrogation? Are boxes just being checked or is there a genuine interest in the subject? We need to adequately prepare for each interaction to ensure we offer a high quality of engagement to all of our partners.

If we approach participants with an attitude of collaboration, might they have more of a vested interest in the project at hand?

## This requires a culture change

It's important to acknowledge that this principle is not the easiest to apply. It requires a complete shift in the way we view our users. Moving from “participants” to “partners” will require a lot of intentional work over time. This won't happen over night and that is okay.

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## Designer-User Relationship

15 minutes

Take some time to reflect on how you would define the relationship between designers and users.

- How does this influence your design process?
  - What outside factors impact this relationship?
  - What would an “ideal” relationship between designers and users look like?
-

## Stakeholder Mapping

45 minutes

Reflect on a project that you have worked on:

- Who were your stakeholders?
- What made them relevant to the project?
- What is the area of expertise for each stakeholder?
- Which of these stakeholder groups did you interact with over the course of the project?
- Who might be missing from this list of stakeholders?

Consider which stakeholders you considered “partners” in this project. Could treating other stakeholder groups as “partners” have benefited this project?

**Feel free to use this map in the next activity: Interaction Mapping**

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## Interaction Mapping

60 minutes

Think about a project that you have worked on:

- Create a timeline of the methods you used throughout this project.
- On that timeline, make note of any interaction you had with a collaborator, stakeholder or participant including what form it took (in person, remote)
- Identify what you got out of each of these interactions.
- Identify what the other parties got out of each interactions.

Reflect on this timeline:

- How would you define the quality of the interactions you had?
- Is the exchange of information and resources equal?
- Where was interaction lacking?

How might you apply the idea of seeking partners, not participants to your process in the future?

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## Methods Spotlight

Consider how we might incorporate this attitude of partnership throughout our design methods. What would it look like to conduct mutual sensemaking of interview data? How might co-creating personas (e.g., see [7], [23]) or journey maps change the way we represent our users?

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## Recognize Diverse Perspectives

Inviting and respecting diverse perspectives throughout the design process will help in forming a more robust understanding of the problem space and stakeholders we're designing for.

We should push back on the idea of designing for a universal perspective and instead recognize the intricacy and individuality that exists within all of us. By embracing tension and working with conflicting ideas, we can force ourselves to truly consider the reality at hand. We can use our positions as designers to advocate for those we're designing for, rather than accepting a generalized point of view.

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### Consider Advisors

Having diverse perspectives on your team as check points and advisory members may help ensure you are inviting diversity throughout your process. Early on, consider involving partners like this to get feedback on your methods and explore alternative approaches.

### Outliers

When going through your data, don't just label something as an outlier and throw it away. Explore unexpected or conflicting pieces of information to see what you can learn, they may help you better understand the diversity of your data.

### Assumptions

It's important that we recognize our own assumptions and biases. Take time to acknowledge what information you know and where it came from. Addressing these biases early and often will help to ensure our findings and solutions support a realistic representation of our users and aren't backed only by our assumptions.

## Throwing out Assumptions

Taking on a project in a space you're not familiar with can help you to address your assumptions early. If the topic at hand is brand new to you - everything you know is an assumption! Adopting a mindset of learning and curiosity can help you to push out any assumed knowledge while welcoming new ideas.

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## Consider Your Full Impact

Design has the ability to effect a wide variety of stakeholders. It's important to recognize **who** will be impacted by the design process as well as **how** they will be impacted. Realize that your work doesn't exist within a vacuum and shouldn't be made within one - therefore, considering a wide variety of contexts and perspectives early on will benefit a project in the long run.

The clearest way to consider impact is by looking at what it is that different parties gain from the design process. Think about the end results and deliverables, these are often information, resources, or products, are all stakeholders involved gaining access to these things?

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## Ecosystem Mapping

60 minutes

Gather a group of 4-6 people who are familiar with your project (colleagues, clients, etc). Brainstorm and list out people (in the form of roles, organizations or names) who fall into each category:

- Who is your primary/target audience?
- Who is your secondary audience?
- Who might be negatively impacted by your project?
- Whose job could be made easier by your project?
- Who might be interested in learning about your project?
- Who might invest in your project?
- Who would want nothing to do with your project?

Use this list to consider how people might be affected by your solutions. Try to talk to as many people as you can from this list early on!

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## Project Deliverables

One way to ensure that everyone gets something out of the design process is to commit to sending project deliverables to anyone who participates. Note that this requires you think through the accessibility of your project outcomes - an academic paper may be appropriate for some but a website might be appropriate for others. Use this as an opportunity to think through what format would be most beneficial for those involved in your project.

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## Think Long Term

It's easy to get stuck thinking sprint by sprint or limit our sights to upcoming milestones, but we have a responsibility to recognize what a project looks like in the long term. The work we're doing and the solutions we define will be sent out into the world and are generally intended to last. We must make sure our project goals align with a longer vision.

We should be considering the sustainability of a solution; what happens once this goes out into the world? What happens once we walk away? We must consider the needs of our solutions and the capacity of our stakeholders to support those needs. If our goals are in line with those of the people we're impacting, we will be more likely to succeed.

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### Checking Boxes

Make sure you're not just checking boxes to get things done. Be intentional about what you do and why you do it. Considering the long term nature of a project can help to put these smaller actions into perspective.

### Finding Attunement

Rather than trying to reach a final understanding of your users, consider trying to find attunement. By acknowledging the fluidity of the people, experiences, systems and knowledge you're working with, you may be less inclined to make assumptions. Framing this process as reaching attunement promotes an attitude that learning is never finished, allowing for iteration.

## Capacity Building

Consider how you might support your partner stakeholders in building their own capacity and fulfilling their potential? Rather than worrying how you will support your project, consider how you might use your role as a designer to foster growth within the people you're working with so that they can support their own projects.

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## Conclusion + Discussion

In this project, I addressed the research question of **how might we promote the use of more inclusive methods in design?** By first focusing on understanding how researchers are doing design work with older adults living with dementia, and expanding to a broad literature review surrounding inclusion in design, I was able to identify a point of convergence. The academic literature presents theories supporting the idea that design could benefit from an integration of interdisciplinary knowledge, critical reflection of methods and intentional interaction with users.

My main contribution in this project was translating these complex theories presented by HCI researchers into a more accessible framework of Engaged Design. With seven principles, Engaged Design helps designers to prioritize critical reflection of their processes in order to interact more meaningfully with their users.

### Future Work

It is important to acknowledge that though the framework of Engaged Design is evidence-based, it is entirely based in academic literature. To validate and ensure Engaged Design is a robust framework, future work should include working with designers and researchers who practice inclusive design methods to iterate on the current framework.

Additionally, Engaged Design could be tailored for more intentional use with vulnerable populations and those who are often left out of the design process. This could include incorporating more specific activities and prompts tailored for specialized populations.

Finally, it is important to widely disseminate this work with both the academic and design communities.

# References

1. Bannon, L. (2011). Reimagining HCI: toward a more human-centered perspective. *Interactions*, 18(4), 50-57. <https://doi.org/10.1145/1978822.1978833>
2. Bannon, L., Bardzell, J., & Bødker, S. (2018). Reimagining participatory design. *interactions*, 26(1), 26-32. <https://doi.org/10.1145/3292015>
3. Bardzell, S. (2010, April). Feminist HCI: taking stock and outlining an agenda for design. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1301-1310). <https://doi.org/10.1145/1753326.1753521>
4. Bennett, C. L., & Rosner, D. K. (2019, May). The Promise of Empathy: Design, Disability, and Knowing the " Other". In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (pp. 1-13). <https://doi.org/10.1145/3290605.3300528>
5. Bennett, C. L., Peil, B., & Rosner, D. K. (2019, June). Biographical Prototypes: Reimagining Recognition and Disability in Design. In *Proceedings of the 2019 on Designing Interactive Systems Conference* (pp. 35-47). <https://doi.org/10.1145/3322276.3322376>
6. Beyer, H., & Holtzblatt, K. (1999). Contextual design. *interactions*, 6(1), 32-42.
7. Cabrero, D. G., Winschiers-Theophilus, H., & Abdelnour-Nocera, J. (2016, November). A Critique of Personas as representations of " the other" in Cross-Cultural Technology Design. In *Proceedings of the First African Conference on Human Computer Interaction* (pp. 149-154). <https://doi.org/10.1145/2998581.2998595>
8. Dombrowski, L., Harmon, E., & Fox, S. (2016, June). Social justice-oriented interaction design: Outlining key design strategies and commitments. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems* (pp. 656-671). <https://doi.org/10.1145/2901790.2901861>
9. Gaver, B., Dunne, T., & Pacenti, E. (1999). Design: cultural probes. *interactions*, 6(1), 21-29.
10. Giacomini, J. (2014). What is human centred design? *The Design Journal*, 17(4), 606-623. <https://doi.org/10.2752/175630614X14056185480186>
11. Harrison, S., Tatar, D., & Sengers, P. (2007). The three paradigms of HCI. *Alt.CHI, Extended Abstracts on Human Factors in Computing Systems*. ACM.
12. Hayes, G. R. (2020). Inclusive and engaged HCI. *Interactions*, 27(2), 26-31. <https://interactions.acm.org/archive/view/march-april-2020/inclusive-and-engaged-hci>
13. Hendriks, N., Huybrechts, L., Slegers, K., & Wilkinson, A. (2018). Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies*, 59, 58-76.

14. Hendriks, N., Huybrechts, L., Wilkinson, A., & Slegers, K. (2014, October). Challenges in doing participatory design with people with dementia. In Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2 (pp. 33-36).
15. IDEO. The Field Guide to Human Centered Design. [www.designkit.org](http://www.designkit.org)
16. Keates, S., Clarkson, P. J., Harrison, L. A., & Robinson, P. (2000, November). Towards a practical inclusive design approach. In Proceedings on the 2000 conference on Universal Usability (pp. 45-52). <https://doi.org/10.1145/355460.355471>
17. Lazar, A., Edasis, C., & Piper, A. M. (2017, May). A Critical Lens on Dementia and Design in HCI. In CHI (pp. 2175-2188). <https://doi.org/10.1145/3025453.3025522>
18. Lazar, A., Feuston, J. L., Edasis, C., & Piper, A. M. (2018, April). Making an expression: Informing design with people with complex communication needs through art therapy. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (pp. 1-16). <https://doi.org/10.1145/3173574.3173925>
19. Lindsay, S., Brittain, K., Jackson, D., Ladha, C., Ladha, K., & Olivier, P. (2012, May). Empathy, participatory design and people with dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 521-530).
20. Mayer, J. M., & Zach, J. (2013, August). Lessons learned from participatory design with and for people with dementia. In Proceedings of the 15th international conference on Human-computer interaction with mobile devices and services (pp. 540-545).
21. Microsoft. Inclusive Design. [www.microsoft.com/design/inclusive](http://www.microsoft.com/design/inclusive)
22. Morrissey, K., Wood, G., Green, D., Pantidi, N., & McCarthy, J. (2016, June). 'I'm a rambler, I'm a gambler, I'm a long way from home' The Place of Props, Music, and Design in Dementia Care. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems (pp. 1008-1020).
23. Neate, T., Bourazeri, A., Roper, A., Stumpf, S., & Wilson, S. (2019, May). Co-Created Personas: Engaging and Empowering Users with Diverse Needs Within the Design Process. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (pp. 1-12). <https://doi.org/10.1145/3290605.3300880>
24. Steen, M., 2008. The Fragility of Human-Centered Design. IOS Press, Amsterdam
25. Wallace, J., Wright, P. C., McCarthy, J., Green, D. P., Thomas, J., & Olivier, P. (2013, April). A design-led inquiry into personhood in dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 2617-2626). <https://doi.org/10.1145/2470654.2481363>
26. World Health Organization. International Statistical Classification of Diseases and Related Health Problems 10th Revision. WHO; 2016

## Appendix: Summary of Thematic Analysis

Code	Source of Data
SJ	Social Justice Oriented Design
F	Feminist HCI
PD	Reimagining Participatory Design
CE	Committing to Empathy
LR	Elsewhere in literature review

	Theme: Critically Reflect on Your Own Work
SJ	Design for Reflexivity: critical, continual reflection of your own processes and position
LR	Make Assumptions Explicit

	Theme: Transparency is Key
SJ	Design for Recognition: support transparency in the process
LR	Be transparent around goals and agendas
PD	Focus on security
PD	Aim for shared trust
SJ	Design for Accountability: inject fairness and accountability into designs
F	Have systems self-disclose their impact

	Theme: Prepare to Adapt
SJ	Design for Transformation: recognize fluidity and malleability are important
LR	Adapt your methods based on the strengths of those you're working with
LR	Allow for many different ways to interact
F	Support a holistic understanding of your partners

	<b>Theme: Seek Partners, Not Participants</b>
CE	Rather than trying to represent others' experiences, seek partners in the process
F	Value participation and take into account the quality of participation
SJ	Design for Reciprocity: aim for equitable relationship between all stakeholders
SJ	Design for Recognition: co-decide what information is important
CE	Mutual Sensemaking
PD	Aim for mutual learning

	<b>Theme: Recognize Diverse Perspectives</b>
F	Pluralism: resist a universal point of view
SJ	Embrace conflict and diverse perspectives
CE	Recognize and work with asymmetry
PD	Sensitivity to social conflict
LR	Respect Individuality
F	Advocacy: avoid working only for the status quo

	<b>Theme: Consider your Full Impact</b>
SJ	Design for Distribution: create equitable access to materials, knowledge, resources and stakeholders
F	Consider the broad impact on various stakeholders across various contexts
PD	Fairness

	<b>Theme: Think Long Term</b>
SJ	Design for Transformation: recognize the long term nature of your impact
CE	Seek ongoing attunement rather than final understanding
CE	Need for long term commitment and iteration on the process

