

# “I’m So Glad I Met You”: Designing Dynamic Collaborative Support for Young Adult Cancer Survivors

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Wanda Pratt

# **YA Cancer and Information Needs**

## **The Interview Study**

### **Findings Related to YA Needs**

### **Implications for Dynamic Support**

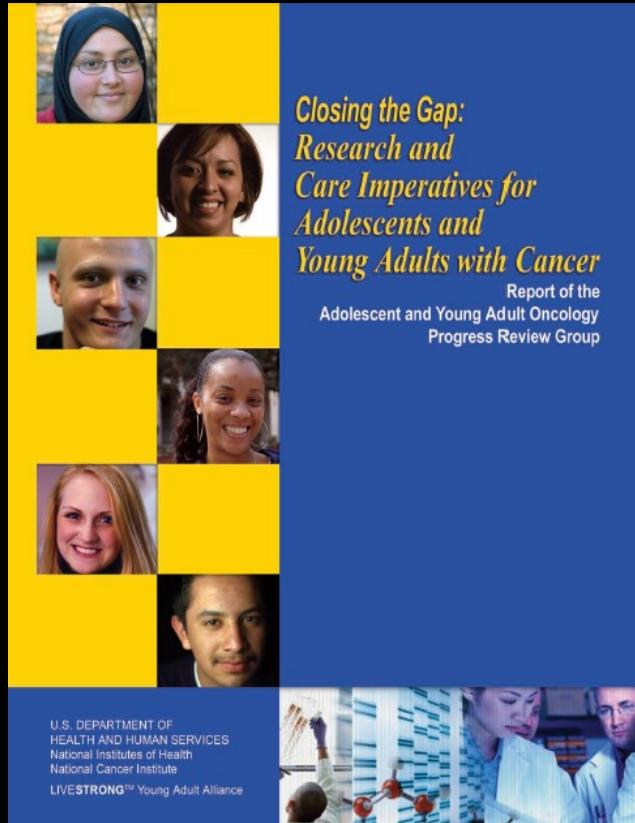
# YA Cancer and Information Needs

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# Information needs for YA cancer



National Cancer Institute  
AYA HOPE, 2006

# YA cancer psychosocial needs\*

Feeling isolated

# YA cancer psychosocial needs\*

**Feeling isolated**

**Confronting a sense of mortality**

# YA cancer psychosocial needs\*

**Feeling isolated**

**Confronting a sense of mortality**

**Struggling with body image/identity**

# Dynamism of support: illness phases\*\*



\*\*Eschler et al., 2015 (ICWSM)

See also Ziebland et al., 2004; Hayes et al., 2008

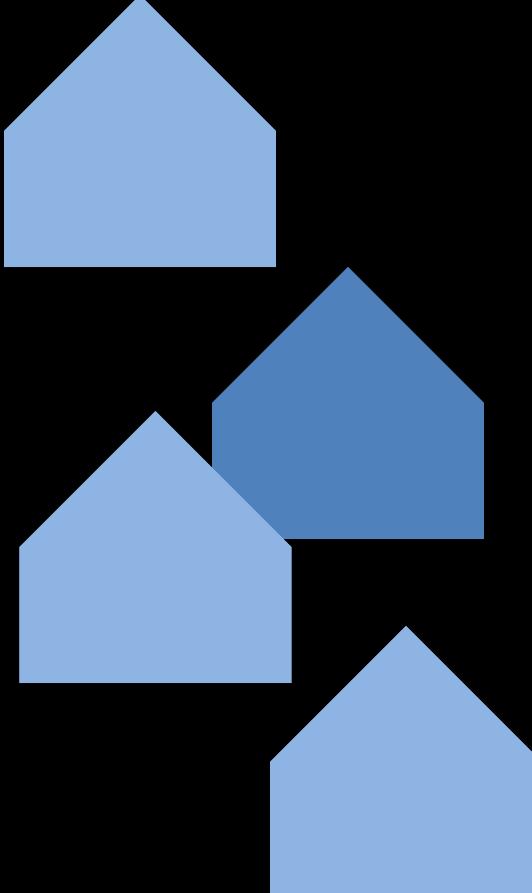
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# Interview procedure



90 minutes

Semi-structured

In participants' homes

N=15 (4 male & 11 female)

# Participants

Pseudonym (Gender, Age)	Diagnosis	Elapsed time from first diagnosis to interview date	General treatment course
Bob (Male, 35)	Hodgkin's Lymphoma, Stage 4	9 months	Chemotherapy
Marie (Female, 42)	Osteosarcoma*	30 years	Surgery, Chemotherapy
Leah (Female, 32)	Breast Cancer, Stage 4	1.5 years	Surgery, Chemotherapy, Radiation
Emily (Female, 35)	Hodgkin's Lymphoma, Stage 3	4 years	Chemotherapy
Jo (Female, 28)	Thyroid Cancer, Stage 1*	2 years	Surgery, radiated iodine
Kate (Female, 29)	Acute Lymphoblastic Lymphoma, Stage 4	4.5 years	Chemotherapy
Lucy (Female, 33)	Acute Lymphocytic Leukemia	4.5 years	Chemotherapy, Stem cell transplant
Peter (Male, 31)	Adenocarcinoma (head & neck)	9 months	Surgery, Chemotherapy, Radiation
Mark (Male, 32)	Brain tumor, Grade 2 or 3	1.5 years	Surgery, Chemotherapy, Radiation
Helen (Female, 31)	Cervical cancer, Stage 1B1	6 months	Surgery, Chemotherapy, Radiation
Michelle (Female, 37)	Cervical cancer, Stage 3	1.5 years	Surgery, Chemotherapy, Radiation
Diana (Female, 30)	Primary Central Nervous System Lymphoma*	2.5 years	Surgery, Chemotherapy, Stem Cell Transplant
Emma (Female, 28)	Thyroid Cancer, Stage 1	11 years	Surgery
J.C. (Female, 34)	Cutaneous T-Cell Lymphoma*	4.5 years	Chemotherapy, Stem cell transplant
Rico (Male, 23)	Acute Lymphocytic Leukemia	3.5 years	Chemotherapy, Radiation, Stem cell transplant

\*Survivor has experienced recurrent or persistent cancer diagnosis

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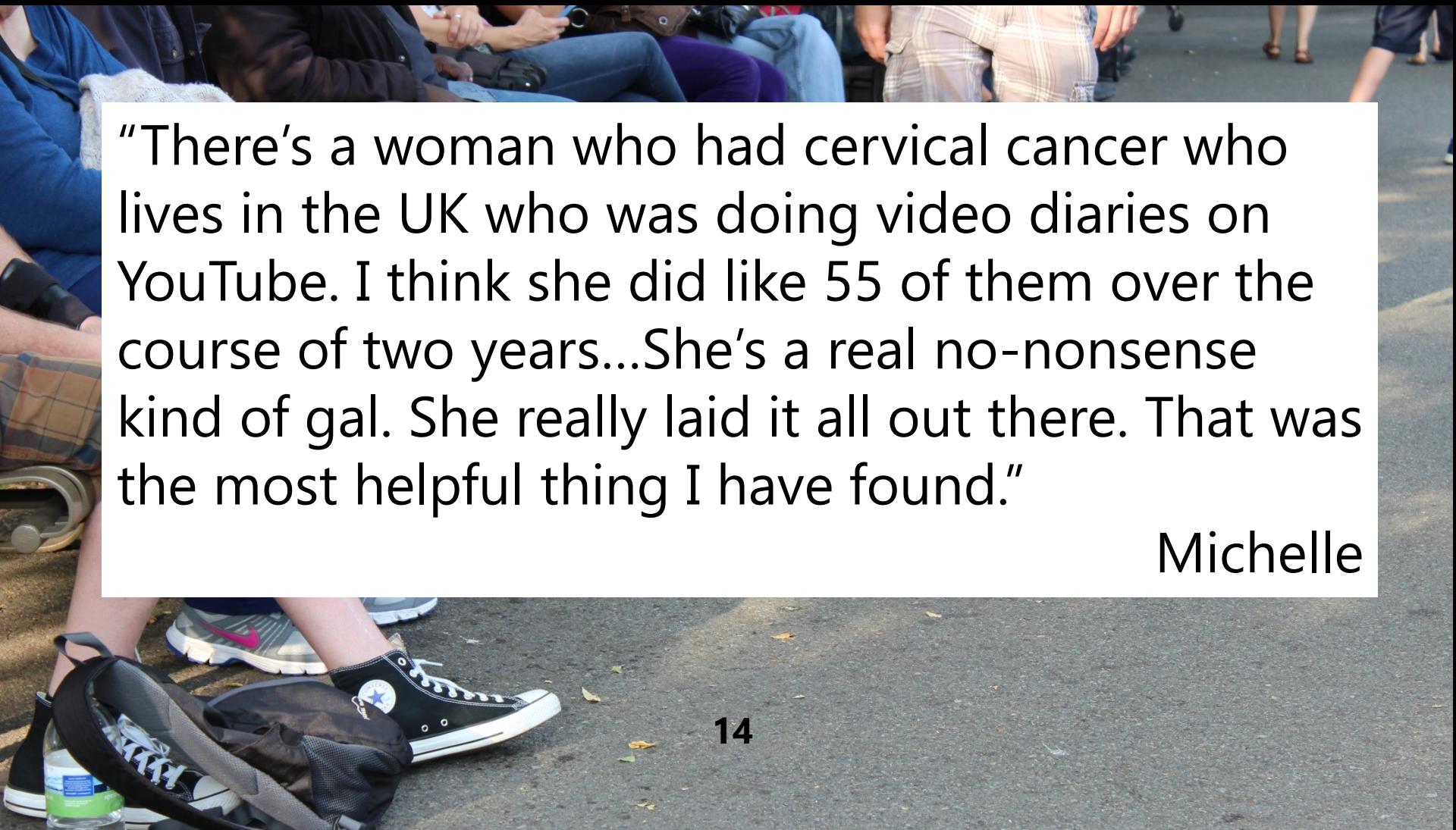
### Findings Related to YA Needs

### Implications for Dynamic Support

# Feeling isolated



# Feeling isolated: adaptation



“There’s a woman who had cervical cancer who lives in the UK who was doing video diaries on YouTube. I think she did like 55 of them over the course of two years...She’s a real no-nonsense kind of gal. She really laid it all out there. That was the most helpful thing I have found.”

Michelle

# Confronting mortality

# Confronting mortality: adaptation

"As far as everybody else is concerned, I'm just going to the coast and we're taking [our son] to the aquarium and just – life is life like it regularly was."

Helen

# Struggling with body image/identity

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# Struggling with body image/identity: adaptation

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"I have a handicap placard [for my car]. Some days I am tired, my back is sore, and I'll use it. If I do use it, people are like [gives side-eye]. I had a lady – it was maybe a couple of months out – and I was just running in to get lunch real quick at Whole Foods and she kind of questioned me."

Leah

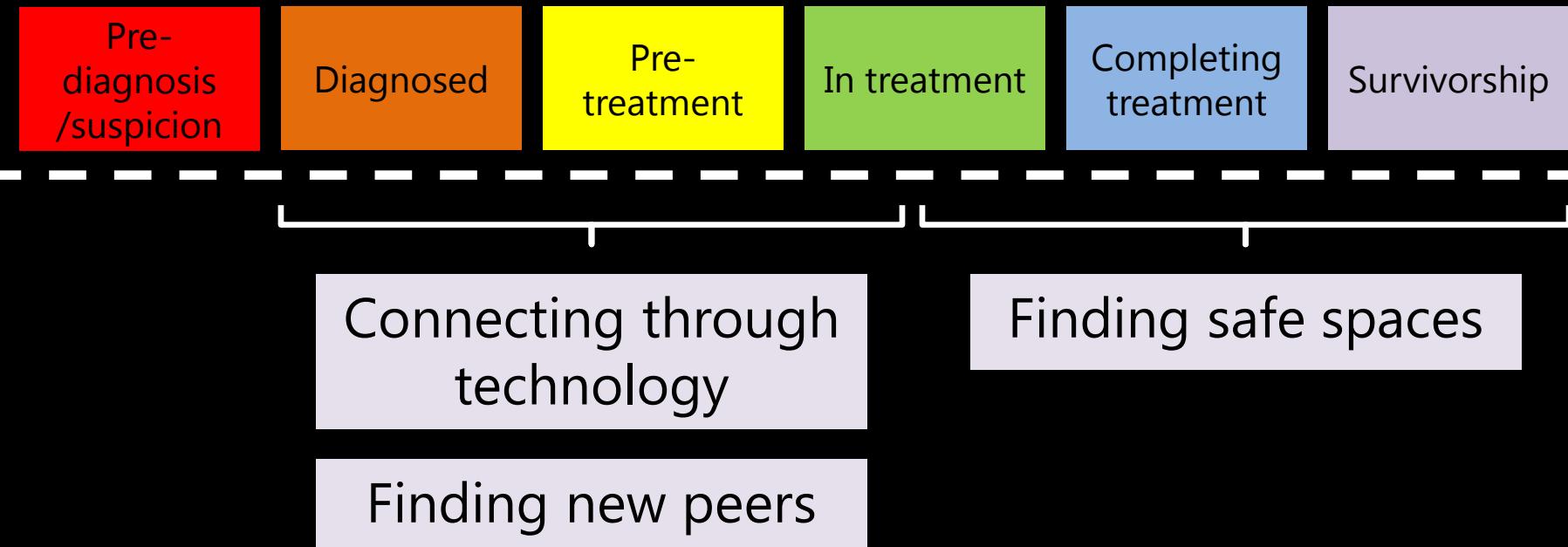
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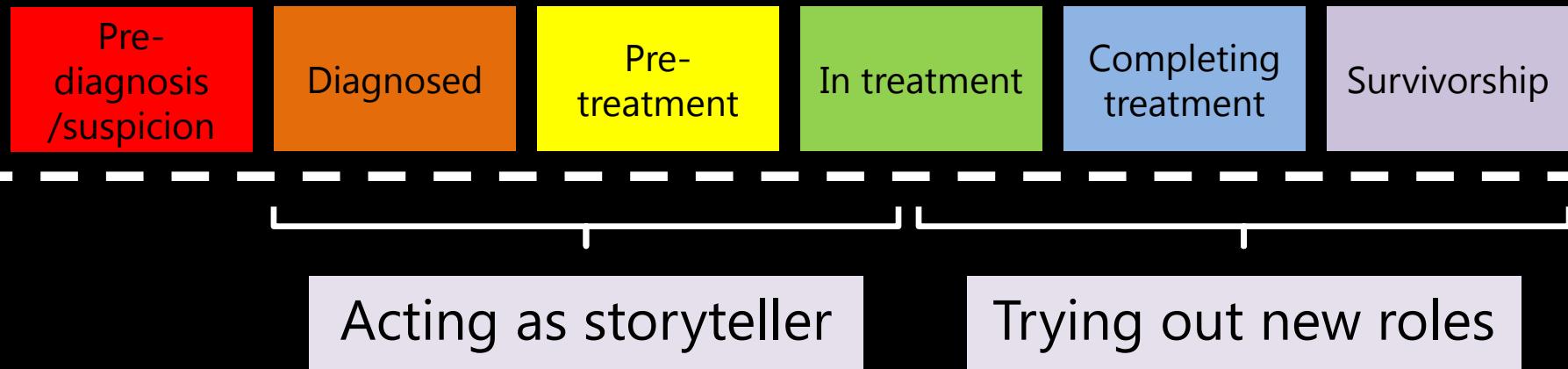
### Findings Related to YA Needs

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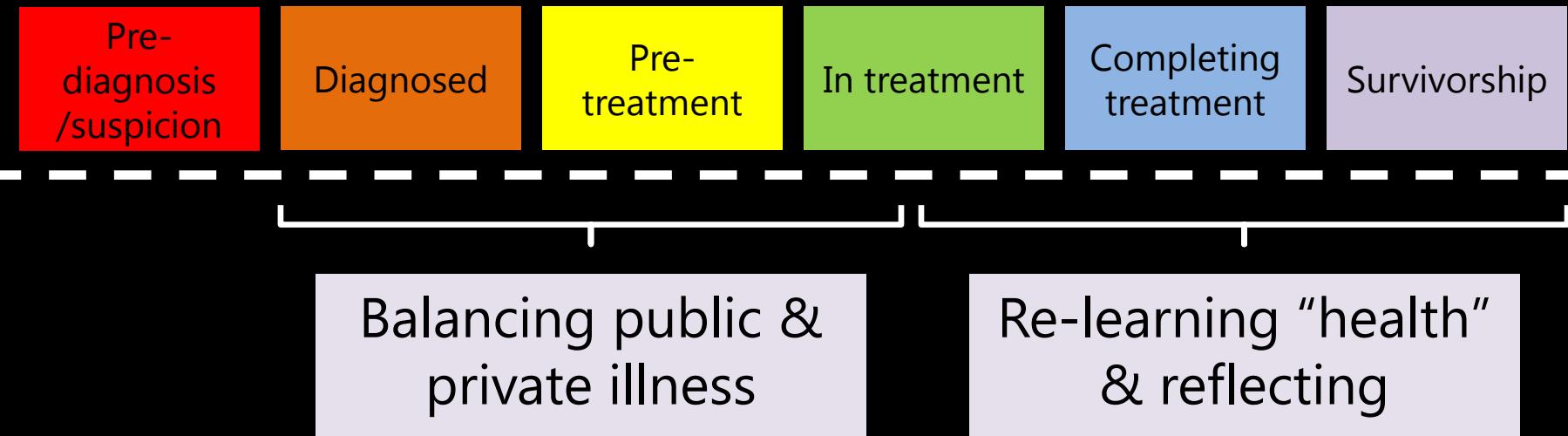
# Feeling isolated: dynamic design = better peer matching



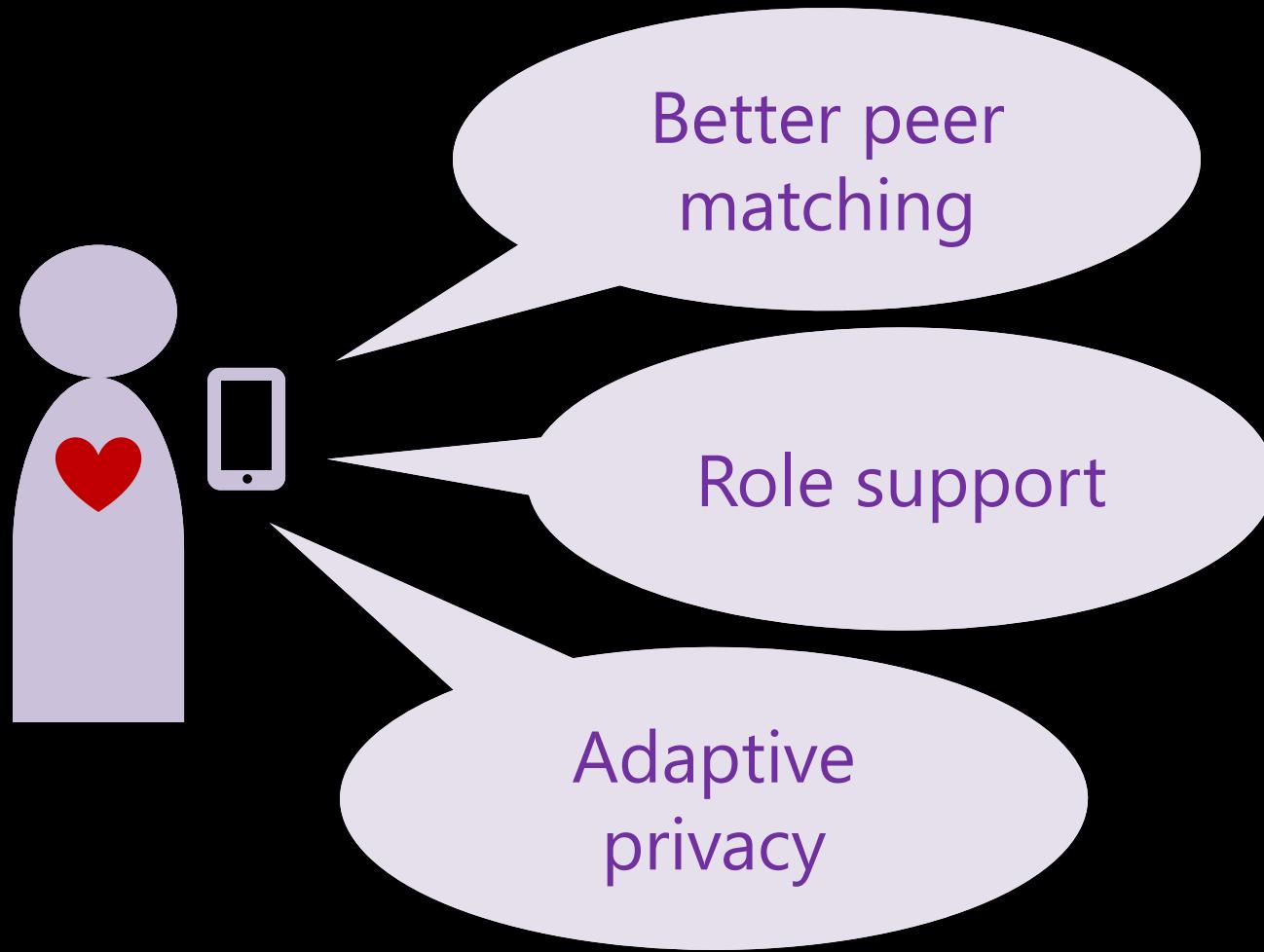
# Confronting mortality: dynamic design = role support



# Struggling with body image/identity: dynamic design = adaptive privacy



# Conclusion: design opportunities



Thank you as always to my research participants

Thank you also to my peer reviewers!

With acknowledgement of funding & support from



# Questions

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 @eschles