CODESIGNING WITH OLDER CONSUMERS:

NEW RESOURCES TO SUPPORT INFORMED DECISIONS ABOUT MANAGEMENT OF KIDNEY FAILURE

Matthew D. Jose on behalf of

Kim Jose, Jan Radford, Rajesh Raj, Lisa Shelverton, Carolyn Baker, Georgia Mc Grath, Jan Priest, Jimmy Ellenberger, David Wightman, Carolyn Gutteridge, Peter Gutteridge.

Acknowledgement of country

This work was undertaken in *lutruwita* (Tasmania) Aboriginal land, sea and waterways. I acknowledge, with deep respect the traditional owners of this land, the muwinina and palawa peoples, their elders past, present and emerging.

CKD.TASlink data: Age 85+ years (from incident eGFR<15 mL/min/1.73m²)

eGFR < 15 mL/min/1.73m²

No KRT

603 days

[322, 984]

(1.6 yrs)

Median Survival (days) [IQR]

2.1 **1.4**

Number of presentations

Proportion free time = 0.96

KRT (dialysis)

757 days

[594, 1170]

(2.1 yrs)

4.6 **1.7**

DAOH-NoD

432 (1.2 yrs)

Proportion free time= 0.69

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AIM:

Making sense of new (Tasmanian) information

Co-design of new decision aids

Decision-making for kidney failure

(if you can't get a transplant)

Supportive Care

Might be attractive to me

I don't want to hang around hospitals.

less clear what it entails (not bricks and mortar)

I am not sure what is around the corner

What will happen if I go down this pathway ?

I'd like more information to help me make a choice

Dialysis

Might be attractive to me

I've seen the machines

I know where it happens

I know I need operations

I know I will be in hospital a bit

I am likely to live a bit longer

…but I'd like more information to help me make a choice

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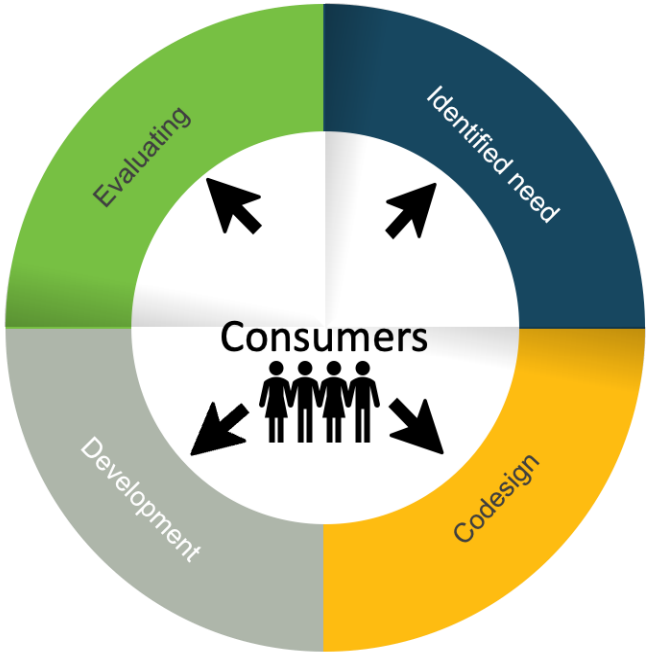
Decision aids Methodology



Phase 1

Identifying what new information is critical to share with consumers and health professionals.

- *Review CKD.TASlink* study data
- Consumer advisory group established (n = 7)
- Consumer advisory group assisted with refining data for focus group discussions

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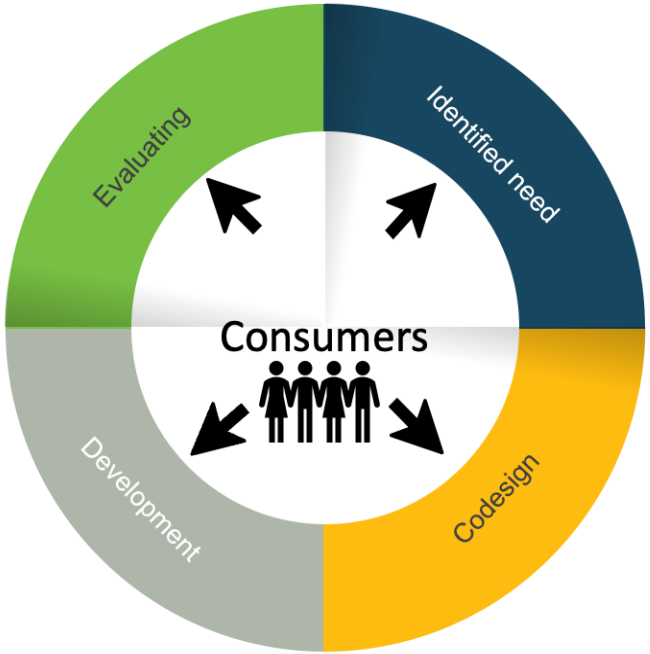

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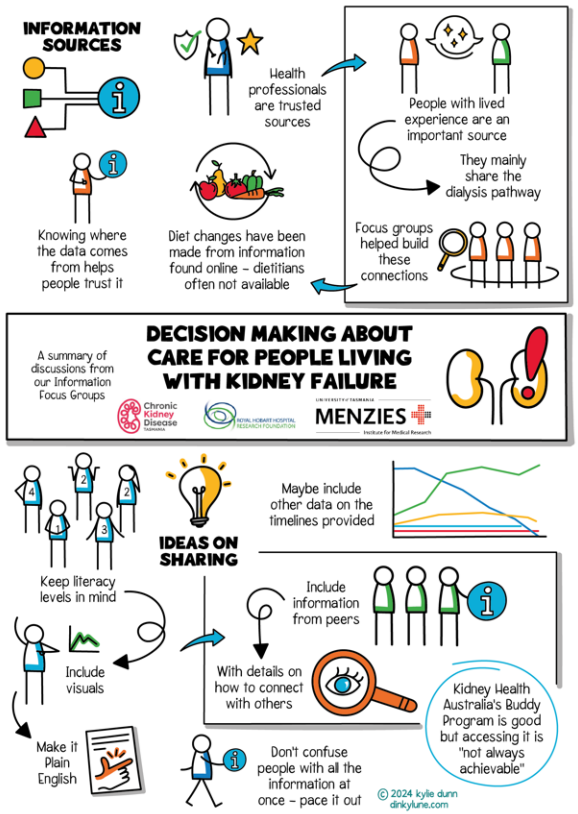
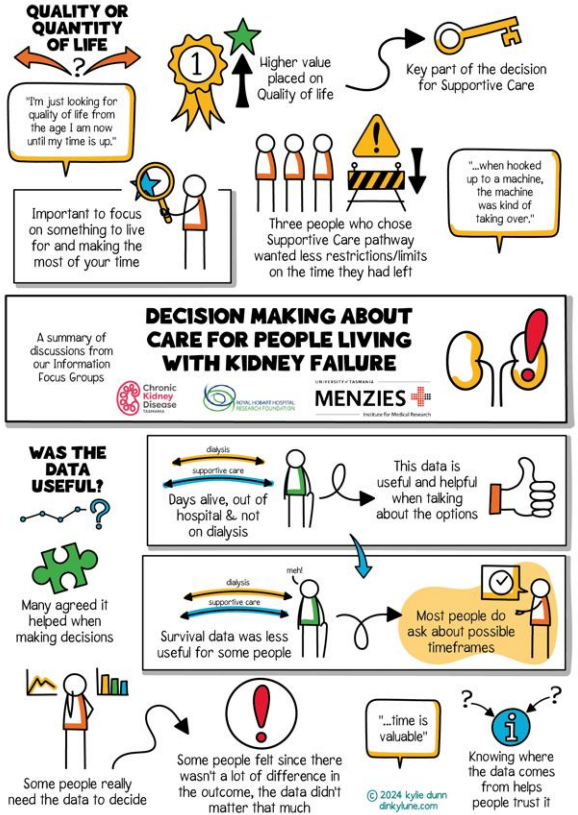
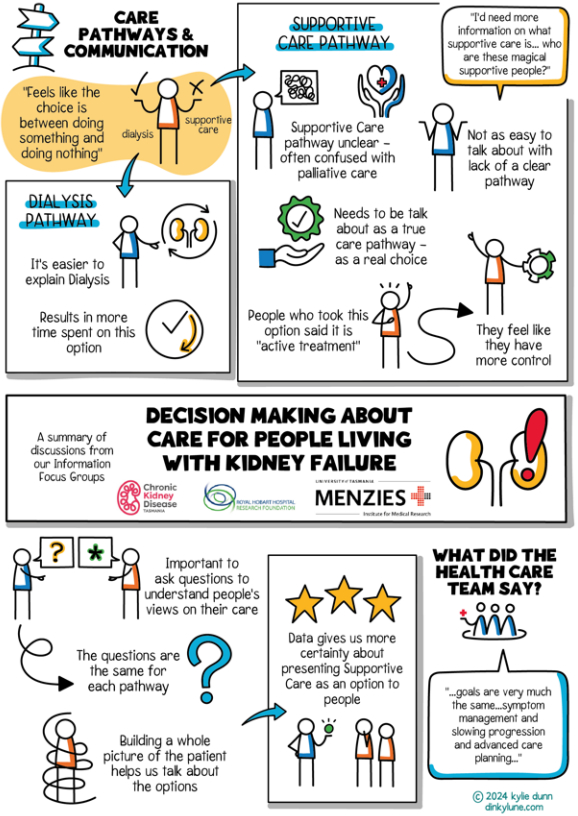
Better information …on what's important …to help make decsions







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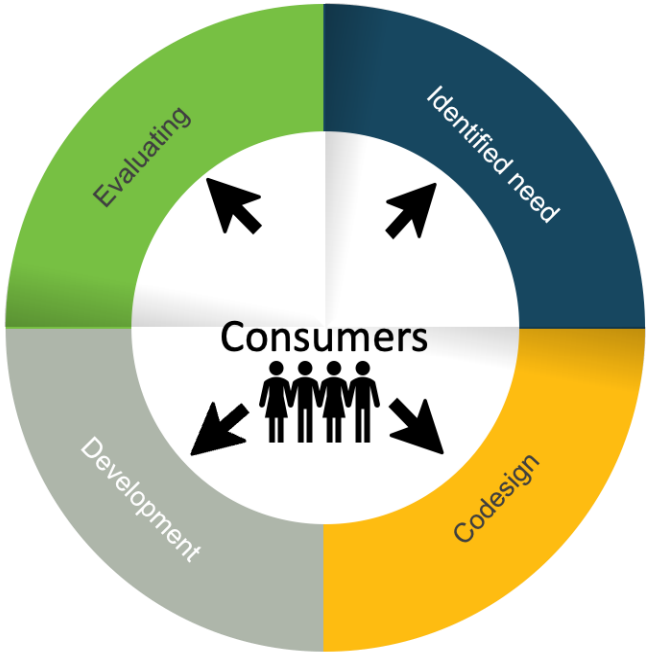

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Phase 3

Development of decision support resources

- Website
- Case studies
- Videos consumers and health professionals
- Written testimonials
- Easy read documents

Decision Making About Care for People Living with Kidney Failure

Home About Consumers Health Professionals Researchers Contact

Making a decision about treatment can be hard.

This website presents findings from a research project. In this project we spoke with consumers and health professionals.

Consumers told us that having more information would help them to think about what is important to them when making treatment decisions.

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These resources are useful for older people living with kidney failure who are not able to have a transplant. Check out the resources below.

About

Learn more about the project and project team.

ABOUT THE PROJECT

Information for Consumers

Information for consumers and carers about making a treatment decision.

RESOURCES FOR CONSUMERS

Information for Health Professionals

Information for health professionals to support consumers and carers about making a treatment decision.

RESOURCES FOR HEALTH PROFESSIONALS

Information for Researchers

Explore the data and published articles.

RESEARCH

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I like to read

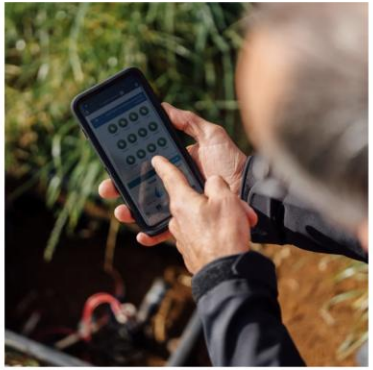
Read case studies to think about what life might be like on dialysis and supportive care.

READ

I like to fill in questions

It can be helpful to think about what is important by filling in this worksheet.

WORKSHEET



I like to look at videos

Watch videos to learn more about supportive care from other consumers, carergivers and health professionals.

WATCH

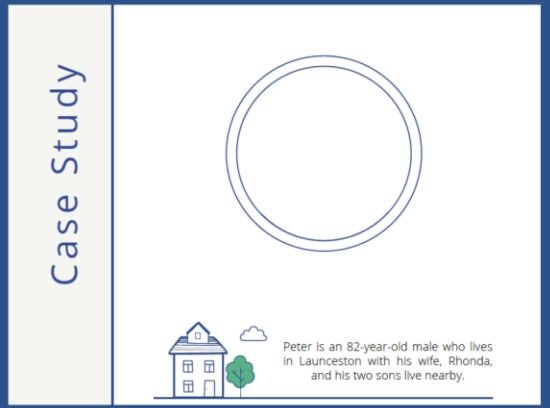
I like to look at diagrams

Look at the data in a diagram to compare dialysis and supportive care.

DIAGRAMS

Case Studies

Meet, Ada and Peter. These are two made-up Tasmanians who have kidney failure. Read the stories of Ada and Peter to see what their life is like on dialysis or supportive care.



Meet Ada

ADA CASE STUDY

Meet Peter

PETER CASE STUDY

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Case Study

Peter

Peter is an 82-year-old male who lives in Launceston with his wife, Rhonda, and his two sons live nearby.

When he was 60, Peter found out he had Type 2 Diabetes. His GP usually takes care of his diabetes. Recently, the GP noted that Peter's kidneys were not working well. He had signs of sickness such as ankle swelling and high blood pressure. Peter says this was a very hard time for him. He did not like hospitals and had felt well for most of his life. Suddenly, Peter was having lots of medical appointments and treatments. This was hard for him to get to as both he and Rhonda were no longer able to drive.

Peter has an estimated **Glomerular Filtration Rate (eGFR)** of 15mL/min. This means his kidneys are not working properly.

Peter needed to talk to his health care team about what to do. Peter thought the only treatment he could have was **dialysis**. Peter's son told him to learn more before making a choice. So, he spoke with the nurses and his medical specialists.

After talking with his medical team, Peter had two treatment options:

dialysis

OR

supportive care

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Peter chooses Dialysis

Peter decides that he would like to start dialysis. But he and Rhonda cannot do it at home. Peter chooses to go to the dialysis unit three days a week. Peter's sons help by driving him there.

At first, Peter felt very uneasy at the dialysis unit. It was a strange setting with lots of machines and new people. Peter says he does not enjoy being on the machines. But now that he has a routine and knows what will happen each time, he feels more comfortable. Peter also enjoys spending time with the nurses and other patients. He often watches television during the long hours of dialysis.

Peter sees his medical team often. He goes to dialysis three days a week. He sees his Kidney specialist every 2 - 3 months. Peter also sees a dietitian and regularly sees his GP. The social worker is looking into community transport to give his son a break from driving.

Since choosing to have dialysis, Peter has needed two operations – one to insert a dialysis **catheter** and another to create a **fistula**. These operations were done so Peter could be connected to the dialysis machine for treatment. He has also had to visit the emergency department twice. This has slowed him down a bit, but Peter is now feeling better.

As his weeks are very busy, Peter likes to take it easy on the weekend. He likes to spend time with Rhonda and his grandchildren.

On the dialysis pathway, Peter may live around three years. This includes about two years of free time (away from dialysis and other medical treatments) while the rest of the time is spent at hospital or on treatment.

Peter chooses Supportive Care

Peter chooses supportive care as he did not want to spend time in hospital or at a dialysis unit. Peter did not want spend time away from home three days a week.

On the supportive care pathway, Peter sees his medical team often. He sees the supportive care nurse when he needs to. He sees his Kidney specialist every 2 - 6 months. He also sees a dietitian and his GP regularly.

Peter has been looking after symptoms (such as fatigue, shortness of breath and restless legs) with his supportive care team. He has started on injections for his **anaemia**. Most symptoms are managed at home. Rhonda is a great support and has changed Peter's diet and reminds him to take his medications.

Peter has been able to keep doing his usual social activities. He attends the Men's Shed and a Friday dinner with friends, although there are some events he misses. Peter has settled into a weekly routine. He enjoys spending time with Rhonda during the week and with his sons and grandchildren on the weekends.

On the supportive care pathway, Peter may live around two years. He would spend most of his time out of hospital and not on dialysis.

	Peter chooses Dialysis	Peter chooses Supportive Care
What contact will Peter have with his medical team?	Peter sees his medical team often. This may include: • GP • Dietitian • Social worker • Psychologist • Pharmacist • Nurse • Kidney specialist • Surgeon • Peter attends the dialysis unit 3 days a week. • Peter has monthly blood tests. These are done when he is at dialysis.	Peter sees his medical team often. This may include: • GP • Dietitian • Social worker • Psychologist • Pharmacist • Nurse • Kidney specialist • Peter has blood tests about every 2-3 months. These are more often now he is treated with **EPO (erythropoietin)**.
How often might Peter go to hospital?	• Before starting dialysis, Peter needs to have surgery to create a fistula (and put in a dialysis catheter) so he can be connected to the dialysis machine. • Since starting on dialysis, Peter has visited the emergency department twice.	• Peter may need to visit the emergency department or stay in hospital. For most people the number of times would be less than if he was on dialysis.
What does Peter's week look like?	• Peter goes to dialysis 3 days per week. He is there for around 5 hours each day. • Peter enjoys the social nature of dialysis. • Peter has reduced his social activities as he is often too tired after his dialysis session.	• Peter can change what he does each day. He has one or two health appointments which he fits around other activities. • Peter keeps doing his regular social activities. Sometimes cancels if he is feeling unwell. • A few times a year, Peter and Rhonda will travel to the west coast to stay with Rhonda's sister for a week.

Easy Read

Care for people living with kidney failure

Help to make decisions

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Chronic Kidney Disease TASMANIA

If you choose supportive care

People on supportive care might have a shorter life than people on dialysis.

People on supportive care spend most of their time out of hospital and do not get as many medical procedures.

What next?

This project might help if you are an older person making a decision between

- dialysis

and

- supportive care.

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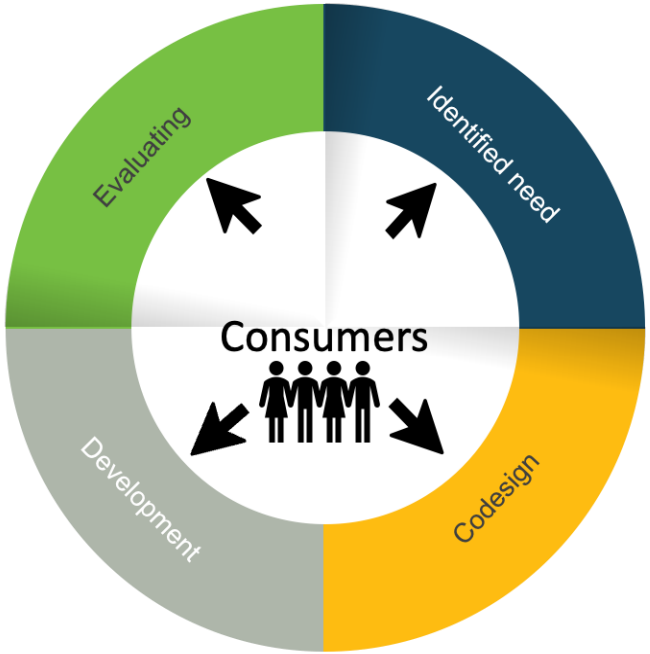
Phase 4

Evaluating usability and acceptability of resources.

- Interviews with consumers and health professionals not involved in development



Conclusion

- Consumers did want information and data but were less interested in the actual numbers
- They wanted to understand how different treatment options compared.
- Important to consider how individuals like to receive information and for HP to provide information in this way ("different people want information in different ways")

- Creation of local resources for decision making
    - Patient stories
        - Video
        - Written
    - Diagrams / Visual aids
    - Table of data or diagram reporting differences

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