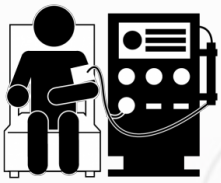
Supplementary Material

Supplementary Figure S1. Patient Invitation to Participate in Workshops

AUSTRALASIAN KIDNEY TRIALS NETWORK

INCH-HD: Starting dialysis in a patient-centred way

Are you interested in having a say about how to do dialysis in a safe and patient-centred way? We invite people receiving haemodialysis (or have received haemodialysis in the past five years) and people who are about to start haemodialysis to an online **INCH-HD patient workshop.** The purpose of the workshop is to discus your views about starting haemodialysis "incrementally" at two sessions per week compared to the "conventional" way of starting haemodialysis at three sessions per week, and your thoughts about what safety in dialysis means to you. Your views will help to inform a clinical trial called INCH-HD.



When:	Option 1 Thursday 24th September 2020; 7 pm - 8:30 pm (90 minutes) Option 2 Friday 25th September 2020; 12:30 pm - 2 pm (90 minutes) Participants attend one session online
Where:	Video conference by Zoom
Reimbursement:	$50
Registration:	http://beatckd.org/inch-hd/
Contact:	Andrea Viecelli on inch-hd.trial@uq.edu.au

The University of Sydney 2020-1567 INCH-HD workshop. This is a voluntary University of Sydney research project. This workshop is organised by The University of Sydney, Australasian Kidney Trials Network and BEAT-CKD.

BEAT CKD
BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE

Supplementary Figure S2. Workshop Program and run sheet

Workshop program and run sheet

WELCOME AND INTRODUCTION (20 mins)

Background/context: Incremental dialysis and why a randomised trial is required

Objective of the day:

- To understand patient and caregiver perspectives on starting haemodialysis at twice a week compared to the usual three times a week including perceived benefits and risks of starting dialysis incrementally.
- To identify, prioritise and discuss outcomes for INCH-HD (ranking).
- To discuss potential enablers, barriers and strategies to maximise recruitment and retention

Confidentiality and voluntary participation

OBJECTIVE 1: INCREMENTAL START TO DIALYSIS – PERSPECTIVES, BENEFITS AND RISKS (20 mins)

1) **Perspective on incremental dialysis**
   a) What are the most important impacts that dialysis (or the need for dialysis) has on your life?
   b) Thinking back when you first started dialysis what were the major challenges you faced and how did you deal with them?
   c) If you had to choose to start haemodialysis at a frequency of three times per week or gently ("incrementally") at twice a week and then increase to the usual frequency of three times a week when required, what schedule would you prefer and why?
2) **Perceived benefits and risks of incremental dialysis**
   a) Do you perceive any specific benefits with starting dialysis at twice a week? Why? (e.g. more time off dialysis/ more time to work/socialise? Less frequent needling?)
   b) Do you perceive any specific risks/safety concerns with starting dialysis at twice a week? Why? (e.g. getting too much fluid built up in the body etc.)
   c) How could these risks be addressed?

OBJECTIVE 2: Identify, prioritise and discuss outcomes for a trial of incremental HD (30 mins)

3) **Identify and prioritise outcomes for a trial on incremental HD**
   a) If a trial was comparing twice weekly to three times weekly start dialysis, what are the outcomes you would be most interested in?
   b) This is a list of possible outcomes to assess in a trial comparing conventional to incremental HD
      Each participant to receive a copy of* **Appendix A.
   c) Are there any that you would like to add – why?
   d) Which of these are the most important – why?
   e) Are there any potential concerns/barriers with any of these – why?
   f) Vote for the top 3 (top priority = 3 points; second top = 2, third top = 1)
   g) Discuss the top priorities of the group based on the overall score given to the different outcomes.
4) **Discuss outcomes for INCH-HD**

a) When assessing your quality of life, what aspects are most important to assess when commencing dialysis? (e.g. physical health, emotional health, pain, mobility)
b) When assessing dialysis-related costs for patients (in addition to the health-care related expenses of dialysis provision) what type of expenses should be measured (e.g. cost for transportation to get to and from dialysis, lost income from inability to work etc)?
c) When measuring residual urine output and residual kidney function, do you think these are important outcomes to measure? Do you think participants would be able to collect urine for 24 hours once a month for the trial? Why? Why not?

5) Discuss triggers to increase the frequency of HD

a) Specific to INCH-HD: The intent of the INCH-HD trial is to randomise suitable participants to start HD at either *twice* a week or *three* times a week frequency. Monthly assessments will be made and if conditions for certain triggers are met such as a reduction in urine output or fluid overload or increase in potassium levels, an increase in dialysis frequency from twice to three times a week will be necessary in the incremental (twice a week) HD group. Have a look at the triggers specified in **Appendix D**, do you think any important triggers are missing or some of the presented triggers are not necessary?
b) If you were randomised to the incremental dialysis group and had met a trigger criterion, would you be willing to increase the dialysis frequency? Why? Why not?

OBJECTIVE 3. RECRUITMENT AND RETENTION (5 mins)

- What would make patients want/not want to participate in this trial?
- What information would you include to motivate patients to participate?
- How should opportunities to participants be delivered/announced?
- When recruiting patients to a trial comparing incremental versus conventional start of dialysis, what would facilitate recruitment and retention of patients in the trial?

PART 3: PLENARY DISCUSSION – 15 mins

Each group will provide a summary of the most important: 1) features of incremental dialysis 2) trial outcomes and 3) critical success factors for trial recruitment and retention

ACKNOWLEDGEMENTS AND CLOSE

Supplementary Figure S3. Patient perspectives and involvement in co-design of a trial of incremental haemodialysis

As part of the INCH-HD Patient Workshop you have registered to attend, we would like to identify and prioritise outcomes (i.e. the impact/effects, both good or bad of a treatment or intervention) that are important to patients starting haemodialysis (HD). This will help to inform the design of a clinical trial that will assess the benefits and safety of starting haemodialysis at 2 sessions per week (incremental HD) compared to three times per week (conventional HD).

The research team have identified several possible outcomes and how to measure these. We will be seeking your feedback on these measures during the workshop (including which one you consider to be the most important outcome), and to suggest other outcomes you think may be important to patients starting haemodialysis.

Outcome	What to measure
Residual kidney function	Loss in patients' own residual kidney function at 6, 12 and 18 months (measured by 24-hour urine collection and blood test).
Mortality	Number of people who die.
Complete loss of urine output	Time until loss of urine output defined as <200ml per day
Vascular access function	Number of vascular access (fistula, graft or catheter) procedures required to enable and maintain the use of a vascular access for HD
Major cardiovascular events	Events involving the heart or blood vessels: cardiovascular death, heart attack, stroke, limb amputation for blocked arteries.
Hospitalisations	Number and duration (days) of unplanned admissions to hospital
Symptom burden	Number and severity of symptoms like fatigue, itch, pain, cramps etc.
Quality of life	Quality of life questionnaires to assess physical and mental health.
Ability to work	Hours and days participants are able to work per week.
Incremental HD duration	How long participants can stay on twice a week HD.
Nutritional status	Assessment of weight, diet, appetite, muscles etc. to assess how well nourished people on haemodialysis are.
Fluid overload	Number of extra dialysis sessions for fluid overload.
High potassium	Number of episodes of high potassium levels (≥ 6.5mmol/L).
Healthcare-related costs	Costs related to haemodialysis treatment and related hospitalisations or procedures.