JANUARY 15, 2018

SUSTAINABILITY OF SHARED HAEMODIALYSIS CARE VERSION 1.1

SHAREHD

DR PAUL LABOI, SONIA LEE, ANDY HENWOOD
SHEFFIELD TEACHING HOSPITAL NHS FOUNDATION TRUST

I. Contents

SUSTAINABILITY OF SHARED CARE (SHAREHD)

1. Introduction

From experience, programs at all levels and in all settings struggle with their sustainability capacity. Unfortunately, when programs such as this one (Shared Haemodialysis Care (SHAREHD) conclude, hard won improvements in public health and in this case Renal Care (Shared Haemodialysis Care (SHC)) can dissolve. To maintain these benefits to the renal community, stakeholders must understand all of the factors that contribute to program sustainability. With knowledge of these critical factors, stakeholders can build program capacity for sustainability and position their efforts for long-term success.

2. SHARED HEAMODIALYSIS CARE Vision

For people who receive dialysis at centres to have the opportunity, choice, education, advise, guidance and ***information*** to participate in aspects of their treatment and thereby improve their experience and their outcomes and for the delivery of this to be standard practice within trusts throughout the renal pathway.

3. Strategy

The approach is to allow individual trusts and teams to maintain their local individuality and exercise shared care as suits and works in their unit – this should include local sustainability strategies (plans) that are highlighted within directorate management meetings through a regular dialogue. Whilst always striving to increase participation, trusts and local units need to educate stakeholders to recognise that there is an ebb and flow especially as patients change (have transplants or pass away) and new patients with different motivations arrive. Furthermore, trusts should work together as 'Hubs' or in 'networks' to share ideas and materials to maintain SHC and for these hubs to work together nationally to ensure coordinated standards and vision.

4. SHAREHD Program Sustainability Goals

It is recognised that the end 2018 timeframe of the SHAREHD program is just a point in time in the movement towards achieving Shared HD care as being 'normal' In Centre Heamodialysis (ICHD) practice and that delivery of shared care should actually span the whole renal pathway. However the constraints of the program mean that not everything can be achieve therefore the specific actions below are those goals that the SHAREHD program aims to deliver.

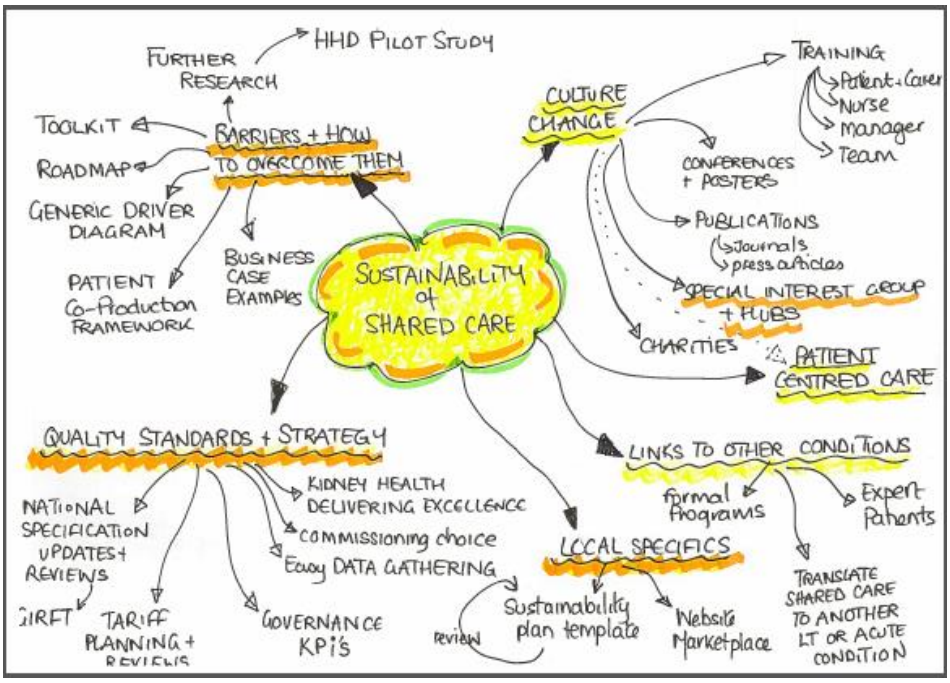
4.1. For each of 12 original trusts to have local sustainability plan/approach (Section 6.2)

4.2. For a wave 3 of an additional 6 trusts to test the Roadmap/toolkit (Section 6.1-A)

4.3. To be a key component of the KQUIP roadmap and Renal Registry (RR) data (Section 6.1 - D)
4.4. For the faculty, including Website, to have a long term 'home'
4.5. Roadmap/Toolkit and generic business cases be available on the website for testing and evaluation.
4.6. Patient Co-Production Framework (Section 6.5-B)

5. Context

The spider diagram below outlines some of the areas for consideration outlined within this document. Section 6 provides more explanation of each component.



6. Context Explanations

6.1. Culture Change

A. SHAREHD related Training

- Nurse Shared Care Course
- Manager Shared Care 1 day course
- Trust level workshops/collaborative – A Third Wave has been agreed to by the Health foundation this is intended to be a 'supported collaborative' to work through the roadmap/toolkit in a structured 6-month program. This will test the validity of such a program with an aim to make it a repeatable 'course' that can become part of the faculty of SHC training.
- Nurse / Doctor / HCP General training and training by 3rd party providers to include Shared Care concepts
- Patient & Carer education
    i. Pre-dialysis and whilst already dialysing
    ii. Pre-start (York Programme)
    iii. In centre Shared Care Videos
    iv. Self-taught / Internet information

B. Journal Publications

Continue to produce local and national articles on Shared Care. Encourage local teams to develop and produce local articles for Hospital papers, Email communications and local newspapers alongside local trust communication team. Articles that may be relevant to produce include

- BJRM Article on Highs and Lows of Patient co-production
- Rework of NKF / KRUK / Kidney Care articles to include Shared Care messages
- Rework of Dialysis Decision Aid to bring Shared Care consideration into play.

C. Conference Presentations

Continue to spread message by providing abstracts where possible, suggest and recommend all trusts to look out for opportunities to present findings approaches etc. Look to have representation at Home Therapies each year and/or have own special Shared Care conference during shared care week.

D. KQUip Ownership

Siting central coordination of SHC vision with KQUIP ensures coordination with key charities KRUK and KidneyCare UK as well as RA and Renal Registry i.e. all key stakeholders are already engaged. Expectation is that this forum will set the direction of improvement travel for the next few years.

In addition the Renal Registry Patient Activation TP-CKD programme had specific Patient activation objectives. SHC is a specific manifestation of patient activation that is key in its own right but is expected to be even better if the whole renal pathway supported and enhanced patients activations levels It is expected that the collection of the Think Kidney Questionnaire may well continue to be collected by RR and will look to be spread nationally.

SHC needs to be supported by regularly collected data that is easily downloadable for local use in KPI slides etc. RR has the tasks collection data already within its dataset (though not mandated) therefore ownership within KQUIP can support this.

E. Renal Charities

Linking and having Shared Care as a central concept within Renal Charities is necessary. Especially charities that are patient focused such as NKF and Kidney care UK. Though important this is not specifically within the SHAREHD programme so is not further explored here.

F. Special Interest Group

This is also not a specific output of the programme however given there is a coordinating mechanism within KQUIP for Vascular access the creation of a shared care special interest group should be considered. . It could be possible that if hosted within KQUIP that the SIG can be a thread within the KQUIP forum with potential steering committees to be held 6 monthly that draw in leads form the regional Shared Care hubs.
Agenda/constitution and terms of Reference should be devised potentially building on the Advisory & Dissemination Board approach and constitution that has been ongoing in the SHAREHD programme..

6.2.Local Specifics

A Trust level Sustainability plans

The aim of these plans is for each local trusts to define what they are doing over the next 6-12 months and how they are going to report this within their trust (local directorate KPIs). No direction is formally given but intent if for local teams to think about what and why they are doing something so that there is a coordinated plan/strategy not just things going on. Direction can be changed over time – template is in 'test mode'

B Learning Logs

Local units should hold lesson learnt logs to ensure that they are building on their own experiences and can share these with others. This can be included in the local plan to ensure it is updated on a regular basis.

C Website Marketplace tools -

These need to continue to be available for local teams to utilise but for there to be a mechanism where new ideas and tools can be added to the site to maintain the sharing of the information.

6.3.Links to other Conditions

This section is to recognise that Shared Care is not specific to Renal. Indeed, it was inspired in part by the Diabetes program of self-care. What is becoming clear is that as a renal community we can support other directorate starting to include share care in their patient interactions . This is true at both a local and national level. What is also clear is that renal teams can learn from other directorates as many of the issues will be similar and the ways to resolve can be applied cross disciplines.

Note: Whilst it is important to make LTC connections, we should remember that the SHAREHD programme relates to patients who attend hospital on average 3 times a week for 18hr per week.

Within the health profession specialisation happens very early in the career, conferences are often focused on specific disciplines and directorates within hospitals are kept very separate which means that cross seeding of ideas is harder to achieve naturally.

Note: Shared Care should be introduced as early as possible to healthcare teachings as it should once a patient is diagnosed.

1.1. Ongoing programs (e.g. Desmond) (might need to expand on this)
1.2. Patient Self-Management programmes e.g. Expert Patients, Peer Support
1.3. Sharing approach with other specialities - Long term or Acute

6.4.Patient Centred Care

- Knowing the patient as an individual: *treating the patient as a person not a disease*
- Essential Requirements of Care: *Respect, Independence, Concerns, Consent and Capacity, Pain management and Personal needs*

- Tailoring healthcare to individual patient's needs: *Unique needs, Preferences and circumstances*
- Including the Patients/carers voice
- Continuity of care and Relationships: *Trust, Reliable relationships, Positive patient experience of effective care*
- Enabling patients to be actively involved in their own care: *Communication, Information, Shared Decision Making, Education*

6.5.Barriers and How to Overcome them

A Patient Engagement

A key aspect of overcoming barriers is to engage patients from the outset both in their own care and in co-production activities.

- Patient Leader development (including Coaching/Mentoring)
- Self-Management/Expert Patient
- Peer Support

B Patient Co-production framework

Framework being created as a result of the patient focus group within the learning events; intent is for this to be a continuum of ways how patients can work in co-production partnership form being part of a MDT (Multi-Disciplinary Team) to proof reading a poster.

C Toolkit

Listing of possible tools available broken down by Quality Improvement, Governance and Training. Where an input is required this will be available from the website and indicated on the toolkit overview. This is a pick list of tools that have worked for others that can be tailor for local use.

D Roadmap

Approach to give trusts and teams a potential pathway to achieve shared care in their unit. To be built and developed through understanding trusts journeys to create a generic pathway using the tools and collaborative support available.

E Generic Shared Care Driver Diagram

Breakdown of motivation and considerations required to deliver the shared care aim / vision. Built up from learning event and conference inputs is a tool for teams

to see where their improvements will fit I to achieving the overall vision of shared care.

F Business Case production

It is suggested that these are to be available in a protected area on the website and will be examples of business cases that have been produced by sites to establish various programs, areas or roles. They will not include the number or financial justifications but will include the what, why and how wording that can take up a large amount of time to create for a business manager if starting from scratch. It would be hoped that the cases include the strategic, commercial , financial and management case for the initiative in question.

Types of cases would include:

- HHD programmes
- Self-Care units
- Patient partners

G. Further Research

Ongoing related studies will take place. It is expected that the overarching Shared Care Strategy could inform and direct these or just be aware of their existence so as to make others aware of what is taking place by way of a loose 'programme'.
Known other studies include

- HHD pilot Study
- SABines HF submission.

6.6.Quality Standards

Organisation	Description	Timescale & Responsible contact
Renal Association Specification Guidelines	NHS England A 06/S/a In Centre Haemodialysis (ICHD) Main and Satellite Units Specifications are currently input driven rather than output driven therefore need rewriting to shift behaviour.	Summer 2017 (TBC) Was Lizzie Lindley Now Damien Ashby End Sept aim 1st drafts End Oct first drafts back End Nov Second drafts all back Early Dec Finalise, perhaps with a half day meeting
Kidney Health Partnership Board Consortium	Kidney Health : Delivering Excellence Initial report produced October 2013 which articulated 16 ambitions that built on the	TBD Co Chairs : Fiona Loud & Hugh Gallagher

	National Service Frameworks produced in 2004 and 2005 - progress report for 2017	
NICE Guidelines (Scope has already been defined for this round of reviews)	Nothing included for Shared Care or patient experience – *suggestion that the review cycle is opportunity to influence.* Nice Guidance CG73: Chronic Kidney Disease Current review is merging Centre, Home, PD and Renal Assessment into a single specification. No current policy for DAFB – Dialysis away from Base which is a key missing component to provide choice to patients.	October 2018 Andrew Mooney Fiona Loud is part of review group.
Clinical Reference Group Linked to NIHR research agenda to ensure focus	Specifications being revised. Needs to be based on routinely collected data Dashboard is being reworked as currently only available to CD and a few others. Suggested to have patient centred Dashboards (3 year timeline) via PREMS/PROMS GIRFT – part of the CRG	Jon Gulliver – Lead Commissioner Richard Baker – Clinical Chair NHS England CRG for Renal Services Will McKane (Sheffield) working on GIRFT.
Care Quality Commission	Regulation 9: Person Centred Care Regulation 10 : Dignity and respect	Last updated 18/3/2015 Last updated 18/3/2015
Dept of Health	The National Service Framework (NSF) for Renal Services Replaced by the Kidney Health: Delivering Excellence report.	DoH 2004/5
NHS England	National Prices and National Tariff Workbook	Updated each year latest prices available at pricing@monitor.gov.uk