The HOUSE Journal
The newsletter for the Year of Care Community of Practice
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Welcome to The HOUSE Journal

Lindsay Oliver, National Director

In this edition of The House Journal we focus on publications and research. We're delighted to draw your attention to the very important recently published BMC Family Practice article that describes how the Year of Care approach to care and support planning (CSP) was developed, right from its original inception and theoretical foundations. It covers the learning and development that has taken place, including revisiting theory when necessary, and the critical success factors for practical implementation. This is a 'must read' for anyone interested in Year of Care and has been well received so far. It is also the BMC Family Practice 'Editor's Pick' this month.

Mostly however we'd like to focus on the work that Dr Sarah Brown has been doing as part of her PhD on a realist evaluation of CSP. Her work highlights the complex nature of CSP and the need to focus on implementation. It reminds me that when we started out we weren't attempting a RCT of CSP. Instead, we were working out how to implement this patient centred approach into routine care based on established theory and evidence of the necessary component parts, and on a strong case for change.

A realist evaluation of care and support planning – Dr Sarah Brown

I recently completed my PhD studying CSP. This was a 4½ year project exploring how, why, for whom and in what circumstances CSP works best. The project used a realist evaluation approach and took place in three phases:

Phase 1: The 'inner workings' of CSP were explored and programme theories identified through review of 51 peer reviewed articles

Phase 2: Theories were discussed and refined during focus groups with expert stakeholders

Phase 3: Theories were tested in practice involving 9 healthcare professionals and 11 people living with long term conditions.

The summary in this House Journal considers how CSP can become so embedded it becomes 'normal' in general practice. I've included a personal perspective of interactions with healthcare practitioners around the health of my son. I hope the findings are interesting and useful to you.

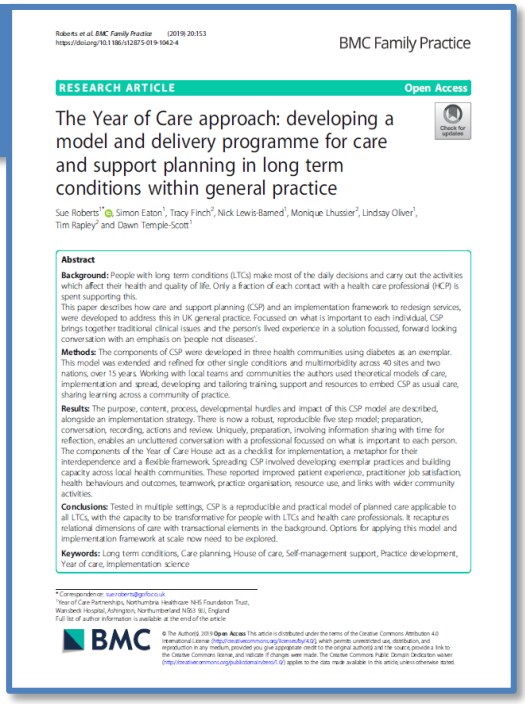
If you would like to read my full PhD thesis, this can be found at: http://nrl.northumbria.ac.uk/41880/

The 'Year of Care Approach' in BMC Family Practice

The paper outlines the methods and results Year of Care have used to develop their approach to CSP over the last 15 years. The paper will be of interest to those involved in CSP, illustrating how components of the approach came together, as well as of interest to academics and commissioners to help understand the combination of published theory and practical testing through implementation, which helped form CSP as it is today.

It concluded that CSP, having been tested in multiple settings and across single and multiple LTCs, is a reproducible and practical model of planned care applicable to all LTCs, with the capacity to be transformative for people with LTCs and health care professionals.

The full paper can be found at https://doi.org/10.1186/s12875-019-1042-4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BMC Family Practice

RESEARCH ARTICLE Open Access

The Year of Care approach: developing a model and delivery programme for care and support planning in long term conditions within general practice

Sue Roberts*, Simon Eaton, Tracy Finch, Nick Lewis-Barned, Monique Lhussier, Lindsay Oliver, Tim Rapley and Dawn Temple-Scott

Abstract

Background: People with long term conditions (LTCs) make most of the daily decisions and carry out the activities which affect their health and quality of life. Only a fraction of each contact with a health care professional (HCP) is spent supporting this.
This paper describes how care and support planning (CSP) and an implementation framework to redesign services, were developed to address this in UK general practice. Focussed on what is important to each individual, CSP brings together traditional clinical issues and the person's lived experience in a solution focussed, forward looking conversation with an emphasis on 'people not diseases'.

Methods: The components of CSP were developed in three health communities using diabetes as an exemplar. This model was extended and refined for other single conditions and multimorbidity across 40 sites and two nations, over 15 years. Working with local teams and communities the authors used theoretical models of care, implementation and spread, developing and tailoring training, support and resources to embed CSP as usual care, sharing learning across a community of practice.

Results: The purpose, content, process, developmental hurdles and impact of this CSP model are described, alongside an implementation strategy. There is now a robust, reproducible five step model; preparation, conversation, recording, actions and review. Uniquely, preparation, involving information sharing with time for reflection, enables an uncluttered conversation with a professional focussed on what is important to each person. The components of the Year of Care House act as a checklist for implementation, a metaphor for their interdependence and a flexible framework. Spreading CSP involved developing exemplar practices and building capacity across local health communities. These reported improved patient experience, practitioner job satisfaction, health behaviours and outcomes, teamwork, practice organisation, resource use, and links with wider community activities.

Conclusions: Tested in multiple settings, CSP is a reproducible and practical model of planned care applicable to all LTCs, with the capacity to be transformative for people with LTCs and health care professionals. It recaptures relational dimensions of care with transactional elements in the background. Options for applying this model and implementation framework at scale now need to be explored.

Keywords: Long term conditions, Care planning, House of care, Self-management support, Practice development, Year of care, Implementation science

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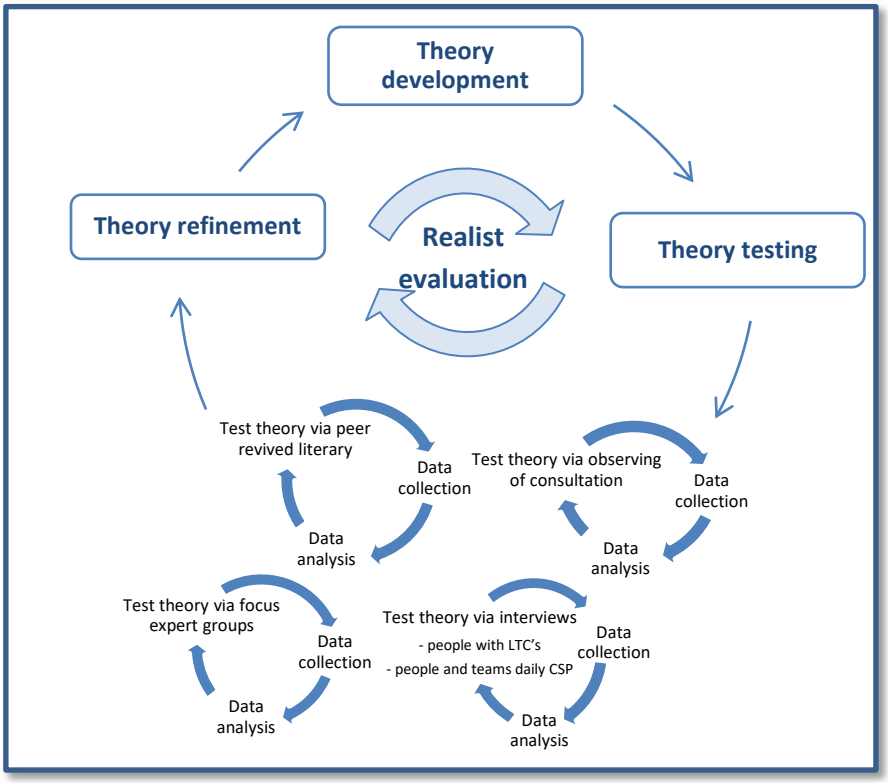
BMC

What is realist analysis / evaluation, and why use it?

CSP is a complex intervention. This means that evaluation is challenging and success cannot be easily described in terms of straightforward cause-and-effect relationships. Realist evaluation explores complex interventions in real world settings.

By understanding the outcomes of these and how they come about theories can be developed to explain what makes an intervention successful; this requires an iterative process. Information used to develop the programme theories come from a variety of sources.

I used a combination of literature review, observation of CSP consultations and training, focus groups, and interviews with people with lived experience, healthcare practitioners, and CSP experts to develop the programme theories of CSP.



What did the research show?

The research successfully explained CSP through the development of 6 tested theories (which should make sense to people involved in or experiencing CSP). Through the systematic 'unpicking' of CSP, these theories were shown to be more than just a 'gut feel' of what might work, but represent tested descriptions of how, why and in what circumstances CSP works best. They show that effective CSP:

1. Begins with preparation of people living with long-term conditions as well as better prepared healthcare professionals.
2. Ensures people with LTC have sufficient time in the CSP conversation to focus on their agenda; the person with LTCs and the healthcare professional collaboratively can make a decision (when a decision needs to be made) and/or set goals; throughout the whole process effective communication is vital.
3. If all of this is done well, support for self-management is achieved.

The 6 tested programme theories are shown opposite.

Quotes from Sarah's research

"When you see it on the piece of paper, you sort of look at it and think oh, it's time to do something. So it made me very aware of my situation […] Looking at the figures in front of you and having them to refer back to from year to year and then seeing the difference – that incited me to start going to Slimming World […] I've certainly got a healthier lifestyle. I've managed to lose up to 5 stone. I would say that I'm at the stage where you can say I've practically reversed it [diabetes]"

★★★★★★★★★★

"We might think that those things don't matter but everything in life impacts on their health and their wellbeing and their condition, so even though we might not necessarily think that that's related, it will be"

★★★★★★★★★★

"It's open questions, empathy, value base, respecting their opinion, giving them time, ask not tell, sharing views, non-judgemental, it's all of that"

★★★★★★★★★★

"Very few people have got nothing they want to change, and if someone was genuinely sitting there saying, "I'm not interested", there would be a massive red flag about mood, about depression, CBT, so there would always be something that we could do to help in some way"

★★★★★★★★★★

The 6 tested programme theories

Statement 1: Preparation

When people with long term conditions and healthcare professionals are prepared for the consultation + and they both have an understanding and belief of the philosophy of care planning = they feel valued and they feel that they have permission to engage and take action → which leads to a more purposeful collaborative conversation

Statement 2: Quality Conversation

When time is spent talking about what is important to the person with long term conditions + in the context of relational continuity and preparedness = the person feels more comfortable, more informed and therefore more in control → so they are more likely to take positive actions (health behaviours, self-management, attitude).

Statement 3: Goal Setting

When both health and social issues are explored + in the context of a quality conversation = people with long term conditions feel better equipped → so they:
a) Become engaged
b) Set goals
c) Become better at problem solving

Statement 4: Shared Decision Making

When a full range of potential actions are shared + in the context of equal power dynamics = there is an open discussion of the pros and cons of each option → and professionals and people with LTCs reach a shared agreement on the course of action

Statement 5: Conversation Summary

When a summary of the conversation is owned by the person with LTCs + and they are involved in discussions and plans about their care = they utilise the summary to check/remind/reflect → which leads to better self-management

Statement 6: Communication

When practitioners use active and open listening, considering holistically the person with LTCs and their social environment + in the context of robust care and support planning = the person feels supported → so they engage in the conversation and share their thoughts and feelings

Quotes from Sarah's research

"He was one of the first patients when we started doing care and support planning and he came in with his form, sat down, and he literally just slapped his yellow form on the desk. Across the front, where it says, "what's important to you?" he had written in big capital letters "PAIN" and underlined it twice. And I just looked at this and said, "ok, you want to talk about pain today" and he came out with "oh, well, I'm sure you won't want to talk about it… 20 years ago doctor so-and-so told me there was nothing that could be done about it so I've just suffered since then but I'm in agony every day". All this stuff came out about this pain and that, twenty years ago a doctor told him that nothing could be done, and he'd been in agony since with his knees and his back. We spent the whole conversation talking about his pain, what could be done about it, how he could be helped to manage that better. I didn't wave a magic wand, I don't think I have a huge amount to make his pain better but by the end of that conversation he was like a changed man.

★★★★★★★★★★

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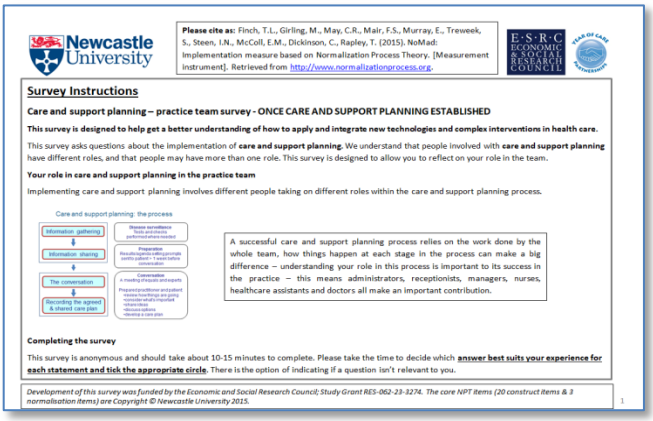
Using Normalisation Process Theory (NPT)

NPT was used in Sarah's research to help understand how individuals and teams go about making sense of and implementing CSP. NPT focuses on what individuals and groups do to 'normalise' a new way of working.

Year of Care has worked with colleagues at Northumbria University in Newcastle, to adapt the 'NOMAD' tool, which measures the domains of NPT and explores 4 key aspects of implementation theory for use in CSP settings.

The tool is a questionnaire that covers 4 main elements:

- Coherence – sense making work
- Cognitive participation – knowingly working differently
- Collective action – operational work
- Reflexive monitoring – appraisal work



Newcastle University

Please cite as: Finch, T.L., Girling, M., May, C.R., Mair, F.S., Murray, E., Treweek, S., Steen, I.N., McColl, E.M., Dickinson, C., Rapley, T. (2015). NoMad: Implementation measure based on Normalization Process Theory. [Measurement instrument]. Retrieved from http://www.normalizationprocess.org.

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Survey Instructions

Care and support planning – practice team survey - ONCE CARE AND SUPPORT PLANNING ESTABLISHED

This survey is designed to help get a better understanding of how to apply and integrate new technologies and complex interventions in health care.

This survey asks questions about the implementation of **care and support planning**. We understand that people involved with **care and support planning** have different roles, and that people may have more than one role. This survey is designed to allow you to reflect on your role in the team.

Your role in care and support planning in the practice team

Implementing care and support planning involves different people taking on different roles within the care and support planning process.

Care and support planning: the process

Information gathering

Information sharing

The conversation

Recording the agreed & shared care plan

A successful care and support planning process relies on the work done by the whole team, how things happen at each stage in the process can make a big difference – understanding your role in this process is important to its success in the practice – this means administrators, receptionists, managers, nurses, healthcare assistants and doctors all make an important contribution.

Completing the survey

This survey is anonymous and should take about 10-15 minutes to complete. Please take the time to decide which **answer best suits your experience for each statement and tick the appropriate circle**. There is the option of indicating if a question isn't relevant to you.

Development of this survey was funded by the Economic and Social Research Council; Study Grant RES-062-23-3274. The core NPT items (20 construct items & 3 normalisation items) are Copyright © Newcastle University 2015.

Copies of the tool are available from: enquiries@yearofcare.co.uk.

Implications for Research?

This realist evaluation comprehensively explored the most favourable contexts, and the mechanisms that are triggered, for 'better conversations' to occur. The findings should encourage us that people with LTCs have healthcare behaviours in their own lives, and that the healthcare practitioner is only one team member around them. It also highlights that CSP requires active strategies to become embedded into practice, the importance of context, how this can affect both implementation and effectiveness, and that this can be facilitated by making use of NPT.

For many healthcare researchers and evaluators, this represents a departure from either a descriptive approach (detailing the intervention) or a focus on effectiveness (does CSP work better than other interventions?).

Thus, in generating evidence-based understandings of the effective implementation of CSP and using NPT to show how it becomes normalised, this study has the potential to inform working practices in many healthcare settings.

Where next – research into self-management for people with LTCs

Dr Lisa Kidd (Reader in Supported Self-Management, University of Glasgow and Associate Editor for Evidence Based Nursing), has produced a blog exploring the growing evidence for supported self-management in people with LTCs and ideas about 'where next?' for researchers.

The blog can be found at: https://t.co/LQ28JiHBgx

My personal experience – Reflections from Dr Brown

During my PhD journey I have had several healthcare encounters which have made me reflect on my own experience of elements of CSP. Before attending appointments where a specialist gave my son a definitive diagnosis and outlined different treatment options I did some preparation of my own.

I took all of this information to the appointment on a piece of paper, confident in my efforts to educate myself about the condition. I still found myself asking my husband, "How will I tell the consultant about my own ideas without undermining his expertise and knowledge?"

Although the consultant was open to me sharing my knowledge, I felt innate awkwardness about doing so. He had initially given me information but actively discouraged me from doing my own research, making me feel that he believed I was incapable of critically reviewing different sources of knowledge. My role as an informed carer was not legitimised, meaning that an equal partnership became very difficult to implement.

My experience brought into focus the importance of professionals being taught specific strategies/tools for initiating partnerships, building trust, identifying expectations for each role and developing plans to follow through on those expectations. That is why preparation is so important for effective CSP.

Once this kind of new practice is initiated, it might become normalised, in professional and personal healthcare practices.

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