

**TRANSFORMING
PARTICIPATION IN
CKD:
INTERVENTIONS
LITERATURE AND
RESOURCES**

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1 Intro

To support the “Transforming participation in Chronic Kidney Disease” programme, a comprehensive overview of existing resources relevant to the interventions listed has been undertaken. This includes both academic literature (published journal articles etc.) and other resources aimed at both patients and staff (eg. educational websites on the interventions and how they may be used).

Each resource found has been presented in the following format: title of resource, a link for ease of location and a short summary including what is contained in the resource and why it is relevant.

The document is split broadly into interventions, with two additional headings: “General Shared Decision Making Resources” and “General Educational Interventions”. The additional headings are to include resources which were felt to be relevant however not specific to a particular intervention. Within each heading, the resources are split into “Academic literature” and “Other Resources”. Other resources can include those aimed at staff and those aimed at patients. The resources may be subdivided further into those specific to renal and those relevant to the intervention more generally.

2 Ask Three Questions

2.1 Academic literature

- Shepherd, H. et al. (2015). Can consumers learn to ask three questions to improve shared decision making? A feasibility study of the ASK (AskShareKnow) Patient-Clinician Communication Model © intervention in a primary health-care setting. *Health Expectations*. <http://www.ncbi.nlm.nih.gov/pubmed/26364752>

Evidence of feasibility and uptake/acceptability of implementing a consumer questions programme. The study concludes that, “This AskShareKnow programme is a simple and feasible method of training patients to use a brief consumer-targeted intervention that has previously shown important effects in improving the quality of information provided during consultations and in facilitating patient involvement and use of evidence-based questions”.

- Shepherd, H. et al. (2011). Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. *Patient Education and Counseling*, 84(3), pp.379-385. <http://www.askshareknow.com.au/Shepherd%20et%20al%20-%20Three%20Questions.pdf>

Evidence of effectiveness of asking three questions on information provided by physicians on treatment options. The study concluded that, “Asking these three questions improved information given by family physicians and increased physician facilitation of patient involvement. Practice implications. These questions can drive evidence-based practice, strengthen patient–physician communication, and improve safety and quality”.

2.2 Other Resources

2.2.1 “Ask Three Questions” resources aimed at patients

- US National Patient Safety Foundation page on Ask Me 3®
 - <http://www.npsf.org/?page=askme3>

Includes posters and an information video. Note: the questions are different to the ones included in the toolkit.

- Pennine Acute Hospitals NHS Trust “Ask 3 Questions Leaflet”
- <http://www.pat.nhs.uk/downloads/patient-information-leaflets/other/Ask%203%20Questions%20Leaflet.pdf>

2.2.2 “Ask Three Questions” resources aimed at staff

- Scottish Health Council, Ask Me 3 and Ask Three Questions.
- http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/ask_me_3.aspx#.V724PIJ0xHh

Information document including tips on how to aid patient understanding, mentions potential resources that may be required.

- The Health Foundation Case Study, “Developing the ‘Ask 3 Questions’ campaign to raise people’s awareness of shared decision making’
- <http://personcentredcare.health.org.uk/resources/developing-ask-3-questions-campaign-raise-peoples-awareness-of-shared-decision-making>

The resource is essentially a report on the introduction of an ‘Ask 3 Questions’ campaign in Cardiff. The report includes considerations made in its introduction, a section on the impact of the campaign and a section on the lessons learned from the campaign. One key lesson identified was that, “strategic launch plans and consultation with all key stakeholders is key for acceptance of the approach and its spread”.

- Cardiff and Vale University Health Board ‘Ask 3 Questions’ Web Page
- <http://www.cardiffandvaleuhb.wales.nhs.uk/ask3>

3 Changes to Practise

3.1 Academic literature

- Nixon, J. and Courtney, P. (2005). Copying clinic letters to patients. *Rheumatology*, 44(2), pp.255-256.
<http://rheumatology.oxfordjournals.org/content/44/2/255.extract?related-urls=yes&legid=rheumatology;44/2/255&cited-by=yes&legid=rheumatology;44/2/255>

A letter describing the results of using this intervention (copying letters to GPs to patients) in a rheumatology department in the UK for 9 months, the department also conducted a survey to attempt to measure the benefit of the intervention. Both patients and their physicians were surveyed and the results were very positive.

- Tomkins, C., Braid, J. and Williams, H. (2004). Do dermatology outpatients value a copy of the letter sent to their general practitioner? In what way and at what cost?. *Clin Exp Dermatol*, 29(1), pp.81-86.
https://www.researchgate.net/publication/8919025_Do_dermatology_outpatients_value_a_copy_of_the_letter_sent_to_their_general_practitioner_In_what_way_and_at_what_cost

Another example of a department using this intervention in practice and then gathering results on its effectiveness. Includes calculations of the cost of this intervention, “the direct total cost of sending a copy letter was 25.3 pence per patient”.

- Lepping, P., Paravastu, S., Turner, J., Billings, P. and Minchom, P. (2010). Copying GP letters to patients: A comprehensive study across four different departments in a district general hospital. *Health Informatics Journal*, 16(1), pp.58-62.
https://www.researchgate.net/publication/43299028_Copying_GP_letters_to_patients_A_comprehensive_study_across_four_different_departments_in_a_district_general_hospital

A more recent study showing that patients do want a copy of GP letters

- Write to the patient and send the copy to the GP
- <http://www.bmj.com/rapid-response/2011/11/02/write-patient-and-send-copy-gp>

A response to an article suggesting that patients should be copied in for medical correspondence; response suggests that letters should be written to patients themselves. Response claims that writing letters directly to patients eliminates concerns regarding copying letters to patients, concerns such as confidentiality and consent. Letters are written in understandable terms and reportedly aid patients to remember what is said during a consultation. Response suggests that programmes are necessary to train doctors to change their writing format to be more patient-friendly.

3.2 Other Resources

3.2.1 Letters to Patients resources aimed at staff

Renal:

- Example of Letters to Patients from CLAHRC CKD team

- <http://clahrc-gm.nihr.ac.uk/wp-content/uploads/Patient-Letters-and-Leaflets.pdf>

General:

- Archived DoH good practise guidelines on copying letters to patients (from 2003).
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4086054.p
- Procedure for Copying Letters to Patients, East Cheshire, January 2014
<http://www.eastcheshire.nhs.uk/About-The-Trust/policies/C/Copying%20Letters%20to%20Patients%20Procedure%20ECT2008.pdf>
- A document outlining the appropriate procedure for copying letters to patients, includes impact assessment.

4 Patient View

4.1 Academic literature

- Phelps, R., Taylor, J., Simpson, K., Samuel, J. and Turner, A. (2014). Patients' Continuing Use of an Online Health Record: A Quantitative Evaluation of 14,000 Patient Years of Access Data. *J Med Internet Res*, 16(10), p.e241.
<http://www.jmir.org/2014/10/e241/>

A study investigating RPV use by patients over time to understand which patients choose to access RPV and the endurance of its appeal for different patient groups. Includes data on: the number of patients registered on RPV at the time (11,352), the percentage of registrants that became persistent users (more than half). Study found that provision of assistance with first logon was strongly associated with becoming a persistent user.

- Hazara, A. and Bhandari, S. (2016). Barriers to patient participation in a self-management and education website Renal PatientView: A questionnaire-based study of inactive users. *International Journal of Medical Informatics*, 87, pp.10-14.
<http://www.ncbi.nlm.nih.gov/pubmed/26806707>

A very recent study looking into barriers to patient participation in Renal Patientview. The study found that patients who were inactive on RPV found it a valuable resource but saw it as a tool to check blood test results leaving other sections of the site underutilized. The study suggests improved promotion of these areas and further development of self-management sections of RPV.

- Woywodt, A., Vythelingum, K., Rayner, S., Anderton, J. and Ahmed, A. (2014). Single-centre experience with Renal PatientView, a web-based system that provides patients with access to their laboratory results. *J Nephrol*, 27(5), pp.521-527.
<http://www.ncbi.nlm.nih.gov/pubmed/24532296>

Study gathering information into how renal patients access and use RPV. It showed that 42% of users accessed their results after their clinic appointments, 38% prior to visiting the clinic. Most users accessed RPV on avg. 1-5/mo. 92% of patients found it easy to use and 93% felt the system helps them in taking care of their condition.

4.2 Other Resources

4.2.1 Patient View resources aimed at patients

- PatientView User Guide for patients
<http://rixg.org/patientview2/howto/user-guide-for-patients/>
- PatientView website
<https://www.patientview.org/#/>

Official PatientView website. Includes instructions on how to join and information regarding services provided. Allows patients to access medical records, letters and information about treatment. Patients are also able to keep track of medications and monitor symptoms using the

website. Patients are able to access PatientView from any location and on mobile devices, they are also able to share their medical information if they so choose.

- PatientView YouTube account
- <https://www.youtube.com/user/renalpatientview>

Videos instructing patients on how to use PatientView. Videos are concise and easy to follow. Note: Captions are not available aside from those which are auto-generated.

4.2.2 Patient View resources aimed at staff

- RPV Recruitment toolkit
 - <http://www.rixg.org/patientview/pages/how-to/recruitment-toolkit.php>

Ideas to help staff to increase usage of PatientView. Notes that the most common reason for not joining PatientView is a lack of awareness. Urges staff to be proactive in recommending PatientView to patients by running recruitment campaigns, using posters and leaflets etc.

5 Patient Decision Aids

5.1 Academic literature

Renal:

- O'Donoghue, D. (2012). Patient decision aids for end-stage kidney disease. *British Journal of Renal Medicine*, 17(4), pp.31-31.

General:

- Cochrane Database Systematic Review (2014), Decision aids for people facing health treatment or screening decisions. Stacey D et al.
<http://www.ncbi.nlm.nih.gov/pubmed/24470076>

Concluded there was high-quality evidence that decision aids improved people's knowledge regarding options, and reduced their decisional conflict related to feeling uninformed and unclear about personal values. Also showed there was moderate-quality evidence that decision aids stimulate people to take a more active role in decision making and improve accurate risk perception.

- Marrin, K., Brain, K., Durand, M., Edwards, A., Lloyd, A., Thomas, V. and Elwyn, G. (2013). Fast and frugal tools for shared decision-making: how to develop Option Grids. *EJPCH*, 1(1), p.240.
<http://ubplj.org/index.php/ejpch/article/view/657>

An article providing guidance for individuals or teams who are interested in developing Option Grids. Contains further information on what option grids are and step by step instructions on how to develop them.

5.2 Other Resources

5.2.1 Patient Decision Aids resources aimed at patients

- Kidney Research UK Decision Aid Booklet for Dialysis Options (Updated in 2015)
- <http://www.kidneyresearchuk.org/file/health-information/KR-decision-Aid-colour.pdf>

Example decision aid booklet currently in use

- Patient info Chronic Kidney Disease Treatment Options - Option Grid
- <http://patient.info/decision-aids/chronic-kidney-disease-treatment-options>

Example Option Grid, includes links to more information about option grids as well as a link to an interactive patient decision aid (<http://optiongrid.org/interactive-app/70?type=guest>)

- Established Kidney Failure Option Aid
- <http://sdm.rightcare.nhs.uk/pda/established-kidney-failure/>

Interactive information guide aiding in treatment decisions regarding EKF. Helps patients decide which treatment is right for them; provides information about EKF, allows patients to compare treatment options and helps patients to identify what is important to them regarding their treatment.

- Kidney Dialysis Treatment Option Aid
- <http://sdm.rightcare.nhs.uk/pda/established-kidney-failure-dialysis/>

Interactive information guide aiding in treatment decisions regarding kidney dialysis. Helps patients decide which treatment option is right for them; provides information about kidney dialysis, allows patients to compare options and helps patients to identify what is important to them regarding their treatment.

- Kidney Transplant Option Aid
- <http://sdm.rightcare.nhs.uk/pda/established-kidney-failure-transplant/>

Interactive information guide aiding in decisions regarding kidney transplants. Helps patients decide which option is right for them; provides information about kidney transplants, allows patients to compare options and helps patients to identify what is important to them regarding their treatment.

- Brighton and Sussex University Hospitals NHS Trust Patient Decision Aid for Kidney Failure Treatment Options (2013)
- <https://www.bsuh.nhs.uk/EasysiteWeb/getresource.axd?AssetID=506131&type=full&serviceType=Attachment>.

Patient Decision Aid booklet discussing options for kidney failure treatment

- York Dialysis Decision Aid and Research Study
- <http://www.yodda.leeds.ac.uk/Survey/Introduction>

A decision aid for patients with CKD, includes instructions on how to use it as well as general education on CKD as well. Contains a link to a study that found that patients were receptive to dialysis decision aid booklet; many patients chose to read the booklet multiple times and share it with family members. Patients liked having information about kidney disease, dialysis and decision making all in one place. YoDDA was endorsed by the European Renal Best Practice Association in 2014 for services related to patients making decisions about dialysis.

5.2.2 Patient Decision Aids resources aimed at staff

- Kidney Health Australia Decision Aid Booklet on End Stage Kidney Disease
- http://www.kidneys.co.nz/resources/file/decision_aid.pdf

Health professional guide to decision making for end stage kidney disease. Includes sections on: What the Health Outcomes and Benefits are of various treatments, the value of decision aids and information on how patients are supposed to use the tool.

6 Motivational Interviewing

6.1 Academic literature

Renal:

- Martino, S. (2011). Motivational Interviewing to Engage Patients in Chronic Kidney Disease Management. *Blood Purif*, 31(1-3), pp.77-81.
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3202953/>

Article contains a section on the applications of MI for CKD.

- García-Llana, H., Remor, E., del Peso, G., Celadilla, O. and Selgas, R. (2013). Motivational Interviewing Promotes Adherence and Improves Wellbeing in Pre-Dialysis Patients with Advanced Chronic Kidney Disease. *J Clin Psychol Med Settings*, 21(1), pp.103-115.
<http://link.springer.com/article/10.1007/s10880-013-9383-y>

Study showed that patients reported significantly higher levels of adherence, lower depression and anxiety levels and better HRQL following regular sessions of Motivational interviewing using the stages of change model

- Sanders, K., Whited, A. and Martino, S. (2013). Motivational Interviewing for Patients with Chronic Kidney Disease. *Seminars in Dialysis*, 26(2), pp.175-179.
<http://europemc.org/articles/PMC3608718>

Contains a section on research about MI for CKD, citing studies which have demonstrated that MI is highly effective in a variety of situations relevant to CKD: including managing diabetes, increasing physical activity, weight loss and improving eating habits.

General:

- Rubak, S., Sandbaek, A., Lauritzen, T., Christensen, B. (2005). Motivational Interviewing: A systematic review and meta-analysis. *Br J Gen Pract* 2005;55:305-12
- <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1463134/>

Report found that motivational interviewing in a scientific setting outperformed traditional advice giving in 80% of studies. Also found that motivational interviewing can be effective in as brief encounters as 15 minutes and that with more encounters, the effect on a patient is increased. Review also identifies that the effectiveness of the motivational interviewing was not dependent on the counsellor's profession as was previously assumed. Review suggests that the effect of the motivational interviewing likely depends on aspects such as duration of the encounter as well as the number of meetings. Review noted that a follow-up period shorter than 3 months caused the risk of counselling failure to decrease. Review concludes that the evaluation of exact methods of motivational interviewing in a clinical setting is lacking and that large-scale studies on how to implement methods of motivational interviewing in daily clinical work are needed.

- Lundahl, Brad and Brian L. Burke. "The Effectiveness And Applicability Of Motivational Interviewing: A Practice-Friendly Review Of Four Meta-Analyses". Journal of Clinical Psychology 65.11 (2009): 1232-1245.
- <http://www.ncbi.nlm.nih.gov/pubmed/19739205>

Report shows that MI has demonstrated itself to be 10-20% more effective than no treatment and as effective as other treatments for a wide variety of problems such as substance use and reducing risky behaviours. MI takes less time than other treatments and has a higher cost effectiveness than the alternatives. MI may work best as a prelude to other treatments and is most effective in a one-to-one setting rather than in a group format. MI can help patients regardless of their age, gender or problem severity and can also be learned by practitioners in a number of professions.

6.2 Other Resources

6.2.1 Motivational Interviewing resources aimed at staff

- Motivational Interviewing Network of Trainers (MINT)
<http://www.motivationalinterviewing.org/>

Contains information on MI trainings and events, latest MI Research, also contains a wealth of resources on MI such as Books, videos etc.

- Et al Training
<http://etaltraining.co.uk/>

Delivers health care training in the UK, puts on Study Days on topics such as MI, CKD etc

- Motivational Interviewing: An Emerging Trend in Medical Management
http://www.patientadvocatetraining.com/wp-content/themes/patientadvocate/static/pdf/ppai_specialreport_mi.pdf

Contains section on what motivational interviewing is, case studies, published research and practical tips on starting an MI initiative.

7 Peer Support

7.1 Academic literature

Renal:

- Taylor, F., Gutteridge, R. and Willis, C. (2015). Peer support for CKD patients and carers: overcoming barriers and facilitating access. *Health Expectations*, 19(3), pp.617-630.
- <http://www.ncbi.nlm.nih.gov/pubmed/25649115>

Study shows peer support is welcomed by patients but there are some barriers that prevent its take-up by many potential users. A major one identified is limited understanding of peer support.

- Hughes, J., Wood, E. and Smith, G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations*, 12(4), pp.396-406.
- <http://www.ncbi.nlm.nih.gov/pubmed/19691464>

Study showed that the majority of patients were overwhelmingly positive about their experience of peer support and its benefits. A brief meeting with a peer supporter delivered similar benefits to those described by participants in support groups.

- Nicholas, D., Picone, G., Vigneux, A., McCormick, K., Mantulak, A., McClure, M. and MacCulloch, R. (2009). Evaluation of an Online Peer Support Network for Adolescents with Chronic Kidney Disease. *Journal of Technology in Human Services*, 27(1), pp.23-33.
- <http://www.scie-socialcareonline.org.uk/evaluation-of-an-online-peer-support-network-for-adolescents-with-chronic-kidney-disease/r/a1CG0000000GaBzMAK>

The evaluation states that online support was strongly valued since healthy peers showed little support.

- Wood, E. (2014). Patient-to-patient peer support in renal care: what, why and how?. *Journal of Renal Nursing*, 6(5), pp.239-243.
- <http://www.magonlinelibrary.com/doi/full/10.12968/jorn.2014.6.5.239>

An article outlining what peer support is, why it is recommended and how it can be implemented. It also contains a section on the evidence of the benefits from peer support. "Peer support has been proposed to benefit patients in a range of physical, emotional and behavioural ways, but to use it appropriately professionals need a realistic, evidence-based understanding of its effects on recipients...impacts on measurable physical outcomes such as mortality, depression or biochemical markers (HbA1c, cholesterol) are small and unreliable...however there is consistent evidence for a number of 'softer' benefits, particularly increased feelings of reassurance, acceptance, improved confidence and ability to cope and participants' satisfaction with the intervention.

- Wood, E. (2014). Patient-to-patient peer support in renal care: examining the role and attitudes of renal clinicians. *Journal of Renal Nursing*, 6(6), pp.293-297.

General:

- Health coaching skills for clinicians to support self-care and behaviour change (CASE STUDY)
- <http://www.nhs.uk/media/2721344/lc-case-study-health-coaching-skills-for-clinicians.pdf>

See case study referred to in comments for "Health coaching in the east of England: promoting patient centred care and behaviour change for people with long-term conditions (National Health Executive, 2015)" in resources below.

- Wood, Eleri. "Peer Support: Increasing Participation Through Clinician Engagement". *Journal of Renal Nursing* 7.4 (2015): 189-193.
- <http://www.magonlinelibrary.com/doi/10.12968/jorn.2015.7.4.189>

The article explores the issue of peer support and clinician engagement. It is split into parts: The first part of the article describes a case study of the peer support programme at King's College Hospital renal unit. It quantifies all activity that occurred over the first 6 years of the programme in order to both evaluate patterns of use and ascertain what influence clinician engagement had on patient participation. The second part of this article explores whether clinician engagement and patient participation could be increased through the implementation of a package of simple interventions.

The article concludes that "active promotion and education about services targeted specifically at clinicians can significantly increase their engagement and thus number of patients who take part. Clinicians should be encouraged to promote peer support equally and routinely to all patients. Future research could include assessment of interventions particularly targeted towards junior clinicians.

- Dennis, Cindy-Lee. "Peer Support Within A Health Care Context: A Concept Analysis". *International Journal of Nursing Studies* 40.3 (2003): 321-332.
- [http://www.journalofnursingstudies.com/article/S0020-7489\(02\)00092-5/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(02)00092-5/abstract)

7.2 Other Resources**7.2.1 Peer Support resources aimed at staff****Renal:**

- Development and Delivery of a Diverse Peer Support Programme for Renal Service Users, their Family and Carers : An Action Research Collaboration (2016)
- <http://www.fons.org/Resources/Documents/Project%20Reports/Development-and-Delivery-of-a-Diverse-Peer-Support-Programme-for-Renal-Service-Users,-their-Family-and-Carers-.pdf>

Report suggests that peer supporters should only be able to commence their training once their commitment to and preferences for peer support have been established. Report also identified a need for patients to be identified for specific peer support roles and linked directly with the relevant HCP in order to increase and improve communication between staff and peer supporters. It was suggested that peer supporters themselves could be trained to deliver peer support training in order to be more efficient, as HCPs are often otherwise occupied. It was also recommended that national renal specialists who have shown interest in peer support should be worked with, in order to promote peer support.

- Coventry and Warwickshire Hospitals Peer Support Programme implementation programme
- <http://www.fons.org/Resources/Documents/Project%20Reports/Development-and-Delivery-of-a-Diverse-Peer-Support-Programme-for-Renal-Service-Users,-their-Family-and-Carers-.pdf>

Contains information on activities peer supporters undertook, the methodology of implementing the programme and challenges that arose when implementing the program

- NHS Kidney Care (2013) You're not alone: peer support for people with long term conditions. NHS Kidney Care, London
- http://static.premiersite.co.uk/45832/docs/5724056_1.pdf

Includes the results from the 2012 National Survey of peer support in kidney care (2012)

General:

- Peer Support: What Is It and Does It Work?, National Voices, Nesta (2015)
- <http://www.nationalvoices.org.uk/publications/our-publications/peer-support>

Report concludes that peer support is worth investing in as patients can have improved behaviour and health outcomes. Patients feel more knowledgeable and confident and less isolated. The report suggests that the three most effective methods of peer support are: face-to-face groups which focus on emotional support and education, one-to-one support and online forums. The report suggests that peer support should be integrated into mainstream services but notes there may be difficulty in doing this without over-professionalising it and losing the 'peer' approach which makes it so effective.

- People Helping People: Peer support that changes lives, Nesta (2013)
- <http://www.nesta.org.uk/publications/people-helping-people-peer-support-changes-lives>

Report finds that peer support allows patients to gain back control over their lives as they are supported in a way that can feel more personal than an appointment with a psychiatrist. Patients were said to find it liberating that they could 'talk at' someone without expecting to be offered solutions and answers; they preferred simply to be heard. Includes video showing the value of integrating peer support into routine care. Peer support can help patients through treatment as the

video suggests that patients are more willing to talk to those who understand what they are going through, people with whom they share life experiences.

7.2.2 Peer Support resources aimed at patients

Renal:

- National Kidney Foundation Peer Support Programme Flyer (2009)
- https://www.kidney.org/sites/default/files/docs/02-10-4196_ebb_benefitsprofessionalflyer.pdf

Comprehensive leaflet containing information on the benefits of peer support, challenges faced by kidney patients and information on how to become a peer partner.

General:

- Patient-Centred Care Resource Centre, The Health Foundation (2014)
- <http://personcentredcare.health.org.uk>

Contains a [Peer Support](#) section containing blogs on the subject.

- Information leaflet on the Peer Support Programme in the University Hospitals Birmingham NHS Trust (2014)
- <http://www.uhb.nhs.uk/Downloads/pdf/PiPeerSupport.pdf>

8 Coaching

8.1 Academic literature

- Wagner, T. (2016). Costs for a health coaching intervention for chronic care management. *American Journal of Managed Care*
- <http://www.ncbi.nlm.nih.gov/pubmed/27143350>

Study found that health coaches have been shown to improve clinical outcomes related to chronic disease management. It also found that employing health coaches adds an additional cost of \$483 per patient per year. The study did not suggest that health coaches payed for themselves by reducing healthcare utilization in the first year.

- Thom, D. (2015). Health coaching by medical assistants improves patients' chronic care experience. *American Journal of Managed Care*.
- <http://www.ncbi.nlm.nih.gov/pubmed/26633093>

Study found that using medical assistants trained in health coaching significantly improved the quality of care that low-income patients with poorly controlled chronic disease reported receiving from their healthcare team.

- Thom, D., Ghorob, A., Hessler, D., De Vore, D., Chen, E. and Bodenheimer, T. (2013). Impact of Peer Health Coaching on Glycemic Control in Low-Income Patients With Diabetes: A Randomized Controlled Trial. *The Annals of Family Medicine*, 11(2), pp.137-144.
- <http://www.ncbi.nlm.nih.gov/pubmed/23508600>

Study showed that peer health coaching significantly improved diabetes control in this group of low-income primary care patients.

- Dennis, S., Harris, M., Lloyd, J., Powell Davies, G., Faruqi, N. and Zwar, N. (2013). Do people with existing chronic conditions benefit from telephone coaching? A rapid review. *Aust. Health Review*.
- <http://www.ncbi.nlm.nih.gov/pubmed/23701944>
- Steventon, A., Tunkel, S., Blunt, I. and Bardsley, M. (2013). Effect of telephone health coaching (Birmingham OwnHealth) on hospital use and associated costs: cohort study with matched controls. *BMJ*, 347(aug06 2), pp.f4585-f4585.
- <http://www.ncbi.nlm.nih.gov/pubmed/23920348>

Study found that telephone coaching intervention did not lead to the expected reductions in hospital admissions or secondary care costs over 12 months, and could have led to increases.

- Jonk, Y., Lawson, K., O'Connor, H., Riise, K., Eisenberg, D., Dowd, B. and Kreitzer, M. (2015). How Effective is Health Coaching in Reducing Health Services Expenditures?. *Medical Care*, 53(2), pp.133-140.
- <http://www.ncbi.nlm.nih.gov/pubmed/25588134>

Study found health coaching led to significant reductions in outpatient and total expenditures for high-risk plan enrollees.

8.2 Other Resources

8.2.1 Health Coaching resources aimed at patients

Renal:

- Recent Information document for a health coaching programme in the US targeted at patients with CKD (2015)
- http://www.blueoptionsc.com/sites/default/files/user_files/documents/bchp_17933_15_blue_option_chronic_kidney_disease_booklet_hr.pdf

Contains sections on, "Is health coaching for me?" and Participant Rights and Responsibilities.

General:

- NHS Horsham and Mid Sussex CCG - Health Coaches
- <http://www.horshamandmidsussexccg.nhs.uk/your-health/health-coaches/>

Contains information of what health coaching is, why it's being introduced and examples of how health coaches can help patients.

- My Health My Way
- <http://www.myhealthdorset.org.uk/How-are-you-managing>

Includes patients' testimonies on how health coaching has helped them, information on what health coaching is and a section on whether 'My Health My Way' is right for individual patients.

Note: Also contains section on information for clinicians and health professionals.

8.2.2 Health Coaching resources aimed at staff

Renal:

- Health coaching for CKD Patients: a Demonstration (2013)
- http://www.slideshare.net/Keryx_Education/coaching-fornursesdemo092912-15832734

A video showing a health coaching seminar for staff, video shows a sample interaction between a health coach and a CKD patient. Also includes to other education videos on the topic of health coaching.

General:

- NHS Health Coaching for Behaviour Change Programme (2015)
- https://eoeleadership.hee.nhs.uk/Health_Coaching

Includes information on what health coaching is, details on the implementation of health coaching in the East of England, Outcomes and Evaluation, Cost effectiveness.

- Health coaching in the east of England: promoting patient centred care and behaviour change for people with long-term conditions (National Health Executive, 2015)
- <http://www.nationalhealthexecutive.com/Comment/health-coaching-in-the-east-of-england-promoting-patient-centred-care-and-behaviour-change-for-people-with-long-term-conditions->

Includes information on what health coaching is, there is a section on “Benefits to patients, clinicians and the NHS” which reports that more than 96% of clinicians were positive about the project in post-training surveys. Also included is results from a case study indicating a 63% indicative cost saving from reduced clinical time, compared to usual non-health coaching approach, giving a potential annual saving of £12,438 per FTE if reduced clinical time was widely replicable and sustainable over time. At the end of the article there are testimonials from health professionals who have tried the approach.

- At the heart of health : Realising the value of people and communities (2016)
- http://www.nesta.org.uk/sites/default/files/at_the_heart_of_health_-_realising_the_value_of_people_and_communities.pdf

Contains information on what health coaching is as well as the benefits and ideas on how to successfully introduce health coaching. Suggests health coaching is more successful when coaches are recruited for their commitment and their emotional needs are met. Also contains data from Being Well Salford, a service which makes use of health coaching. After twelve months of using the service it was reported that 93% of participants believed they had an increased awareness of opportunities and services. 88% said they had adopted at least three behavioural change goals within six months and 70% had increased their self-efficacy significantly.

9 K-HOPE

9.1 Academic literature

9.2 Other Resources

9.2.1 K-HOPE resources aimed at staff

- HOPE Programme Coventry website (2016)
- <https://hopeprogramme.coventry.ac.uk/courses/HOPE-Courses-Overview.aspx>
Contains the majority of information available on the HOPE programme.
- Macmillan Cancer Support Final Report on HOPE (August, 2011)
- http://www.ncsi.org.uk/wp-content/uploads/HOPE-Final-Report_-August-2011.pdf

An example of how the HOPE programme was implemented in practise, in this case for cancer patients. The report linked to is quite comprehensive, covering things such as: the methodology of recruiting participants to the course, the profile of the participants, effects of the course on the participants QoL, effects on health service utilisation, effects on diet, effects on perceived health and self efficacy etc.

- HOPE programme in the West Midlands for Alzheimer's Patients
- <http://wmahsn.org/programmes/view/hope-programme>

The programme is currently in progress; the page contains a list of programme outcomes providing details of the project. "The HOPE programme seeks to develop, refine and evaluate an online dementia self-management programme for people living with early stage dementia and their supporters to deliver greater control for people with dementia and their carers and a freeing up of resources in mental health and community services".

9.2.2 K-HOPE resources aimed at patients

- Lynda Jackson Macmillan Centre's HOPE Page
- http://www.ljmc.org/4_about_us/news_autumn_2013/hope_patient_perspective.html

Contains a piece from a HOPE participant, talking about what she gained from the course.

10 Communication Skills

10.1 Academic literature

- Levinson W, Lesser CS, Epstein RM. Developing physician communication skills for patient-centered care. *Health Affairs*. 2010 Jul 1;29(7):1310-8
- <http://content.healthaffairs.org/content/29/7/1310.full>

Evidence that communication skills can be taught and how to enhance it and develop it through training, as well as how it can be assessed.

- Nunes JA, Wallston KA, Eden SK, Shintani AK, Ikizler TA, Cavanaugh KL. Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease. *Kidney international*. 2011 Dec 2;80(12):1344-51.
- <http://www.sciencedirect.com/science/article/pii/S0085253815549879>

A study into the relationship between objective and perceived patient knowledge about their condition (CKD) and satisfaction with physician communication

- Lee SJ, Back AL, Block SD, Stewart SK. Enhancing physician-patient communication. *ASH Education Program Book*. 2002 Jan 1;2002(1):464-83
- <http://asheducationbook.hematologylibrary.org/content/2002/1/464.short>

An overview of research aimed at improving patient outcome through better physician-patient communication and discuss guidelines and practical suggestions immediately applicable to clinical practice. The article concludes that better doctor-patient communication can help to identify possible mental illnesses, can lead to better care and reduce the stress on doctors after being informed of communication skills.

- Stewart M, Brown JB, Boon H, Galajda J, Meredith L, Sangster M. Evidence on patient-doctor communication. *Cancer*. 1999 Feb;25:30.
- https://www.researchgate.net/profile/Heather_Boon/publication/12824847_Evidence_on_Patient-Doctor_Communication/links/56732d4208aee7a42743759d.pdf
- Back, A., Arnold, R., Baile, W., Fryer-Edwards, K., Alexander, S., Barley, G., Gooley, T., Tulsky, J. "Efficacy Of Communication Skills Training For Giving Bad News And Discussing Transitions To Palliative Care". *Arch Intern Med* 167.5 (2007)
- <http://archinte.jamanetwork.com/article.aspx?articleid=769642>

A study evaluating the efficacy of a residential communication skills workshop in changing the way communication occurs. Article notes the importance of good communication skills, especially when the patient in question has a life-threatening illness. Article suggests that in training, communications content must be integrated with biomedical content and that the teaching should include skills practice.

10.2 Other Resources

10.2.1 Communication Skills resources aimed at staff

- BMJ Improving your communication skills (2012)
- http://careers.bmj.com/careers/advice/Improving_your_communication_skills

Article aimed at medical students and healthcare staff exploring the art of clear communication in medicine and the steps that doctors can take to improve their communication with patients, family and colleagues.

- BMA Communication Skills (Updated June 2016)
- http://careers.bmj.com/careers/advice/Improving_your_communication_skills

Contains links to Courses and events for communication skills improvement and also provides links for further reading on the subject.

- BMA Communication skills education for doctors: an update (2004)
- http://bmaopac.hosted.exlibrisgroup.com/exlibris/aleph/a21_1/apache_media/AARUJBSG_PV2N6P4LGSRMKYY39IFVVPF.pdf

Education booklet on communication skills for doctors. Includes sections on: The benefits of good communication skills, the profession's need for communication skills training, barriers to effective communication, communication skills in undergraduate and postgraduate education.

- Communication Skills in Palliative Care, A Practical Guide (2001)
- http://www.cornellcares.org/education/pdf/Communication_skills_in_palliative_care_A_practical_guide.pdf

Highlights the importance of effective communication between the doctor and patient and offers practical advice on how to achieve this.

- Communicating at the end of life, Nursing Times (2011)
- <https://www.nursingtimes.net/student-nt/communicating-at-the-end-of-life/5028162.article>

Offers practical advice to student nurses about how best to communicate with patients in palliative care

- Effective communication in palliative care, RCNI (2005)
- <http://journals.rcni.com/doi/pdfplus/10.7748/ns2005.12.20.13.57.c4024>

Highlights importance of communication skills and the need for healthcare professionals to develop their communication skills to as to facilitate the process of communication with the patient.

11 Educational Interventions in General

Academic literature

- Lopez-Vargas, P., Tong, A., Howell, M. and Craig, J. (2016). Educational Interventions for Patients With CKD: A Systematic Review. *American Journal of Kidney Diseases*, 68(3), pp.353-370.
- A systematic review looking at educational interventions for patients with CKD. The study concluded that, “Well-designed, interactive, frequent, and multifaceted educational interventions that include both individual and group participation may improve knowledge, self-management, and patient outcomes”.
- McCarthy, K., J. Sturt, and A. Adams. "Types Of Vicarious Learning Experienced By Pre-Dialysis Patients". *SAGE Open Medicine* 3.0 (2015)
- <http://smo.sagepub.com/content/3/2050312115580403.full>
- The article explored data from a wider study in specific relation to the types of vicarious learning experiences reported by pre-dialysis patients. It found that, “exploration and acknowledgement of service users’ prior vicarious learning, by healthcare professionals, is important in understanding its potential influences on individuals’ treatment decision-making. This will enable healthcare professionals to challenge heuristic decisions based on limited information and to encourage analytic thought processes”.

12 General Shared Decision Making Resources

Renal:

- British Journal of Renal Medicine Supplement 18
- http://www.bjrm.co.uk/Data/Sites/3/supplements/bjrm-18_1-kidney-care-supp.pdf

Contains sections on most of the interventions included in this toolkit as well as some discussion on the importance of implementing shared decision making into practise.

General:

- RCP Shared Decision Making Event - Summary of Learning (2011)
- http://www.renal.org/docs/default-source/what-we-do/Shared_Decision_Making_Report_Final.pdf

Covers many of the interventions included in this toolkit within general discussion

- Desroches, S. (2010). Shared decision making and chronic diseases. *Allergy, Asthma & Clinical Immunology*, 6(Suppl 4), p.A8.
- <http://aacijournal.biomedcentral.com/articles/10.1186/1710-1492-6-S4-A8>

The article includes reference to potential barriers to implement shared decision making including: lack of applicability due to patient's characteristics, lack of applicability related to the clinical situation. In contrast to this; factors such as the health professional's motivation, positive impact on the clinical process and positive impact on patient outcomes are often seen as facilitating the adoption of SDM.

- MAGIC: Shared decision making, The Health Foundation
- <http://www.health.org.uk/node/184>

Contains link to an evaluation of MAGIC programme which states that although it can be challenging, shared decision making can create positive change. It is suggested that starting small is effective when introducing shared decision making as it requires changes in attitude, skills and infrastructure which may be difficult on a large scale.