

Patient involvement in Quality Improvement

How a patient group successfully created
and delivered tools for professionals and
patients to help people to help themselves

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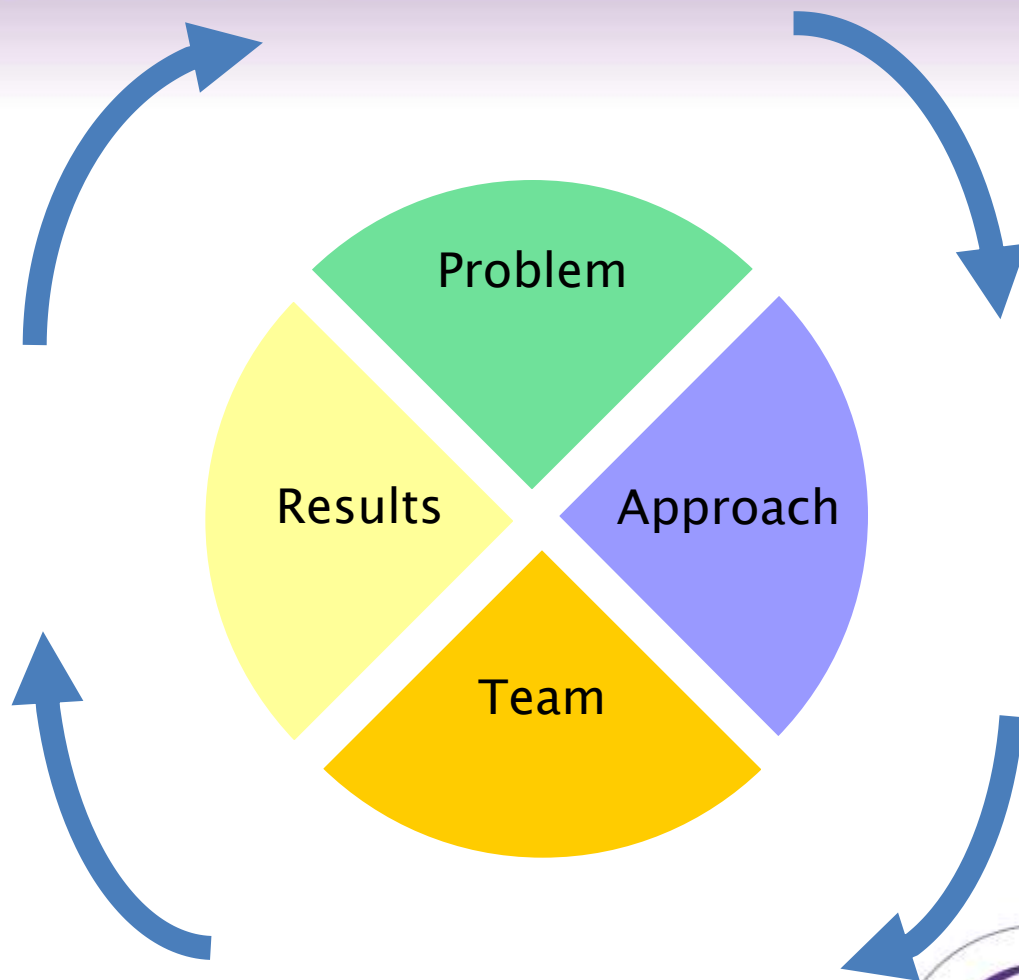
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ENABLE-CKD

Enhancing Care and Saving Lives of People with CKD



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A long-term condition – harmful and can be treatable

- Kidney disease affects 6–7% of the adult population but only about 4% are diagnosed.
- Most have mild to moderate disease but increased cardio-vascular risk and are looked after in the community.
- People with early disease don't know they can help themselves and/or their healthcare practitioners may be unskilled in how best to support self-care.

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What did we do?

Used a 'care bundle' to reduce variation by applying interventions at the same time:

- 3 clinical interventions PLUS offering the patient information about looking after themselves.
- Set up a team of 6 with various long-term conditions (kidney, diabetes, heart) and over 2 years created a set of materials for doctors, nurses and patients using **Plan, Do, Study, Act**.

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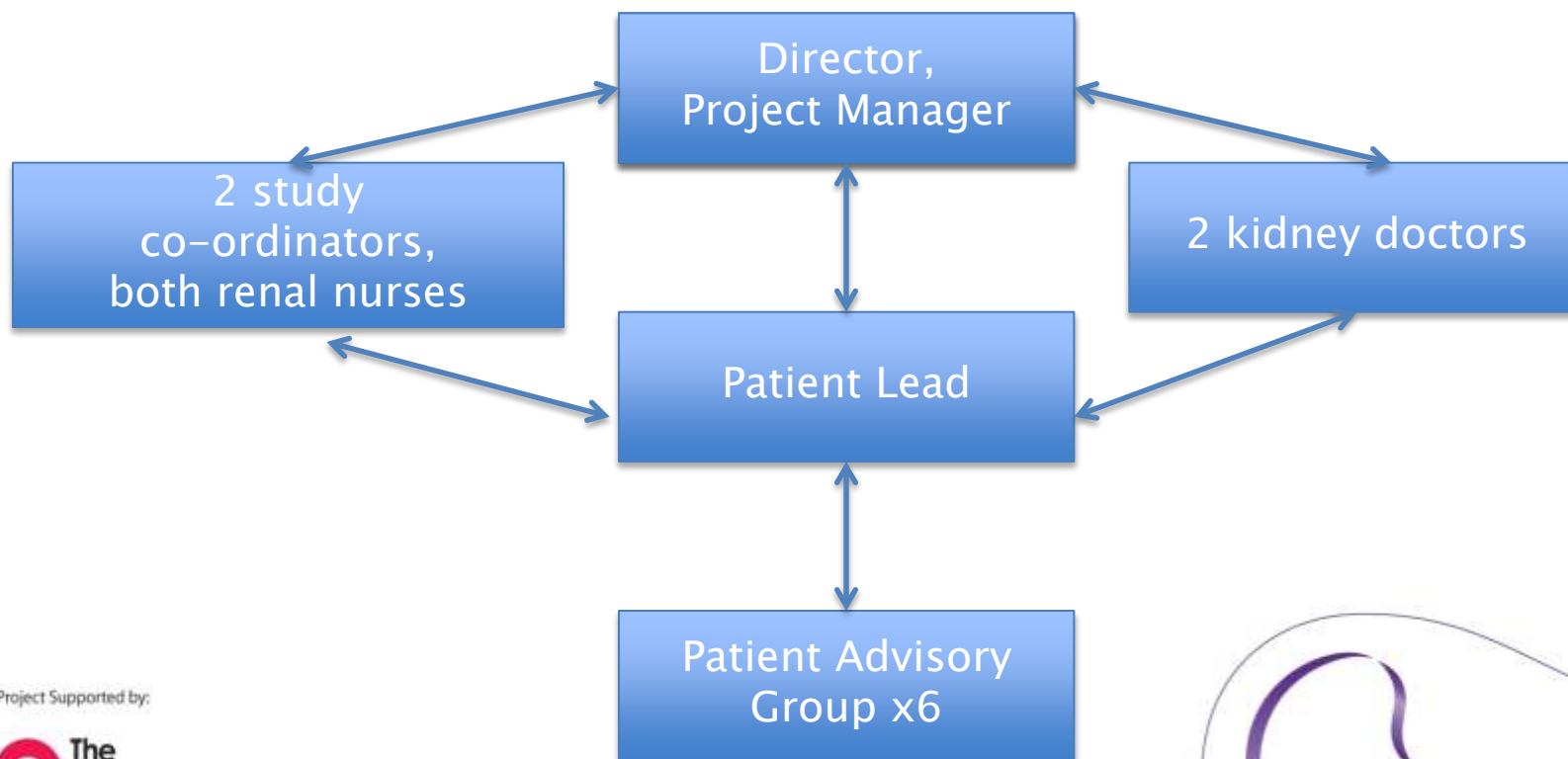
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Operations Team Structure



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The patient team developed and delivered

Patient Packs

Practice Training

Advice to ops team,
practices and
people with CKD

Patient Training

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Patient Team

- Role descriptions, honoraria at same rate as professionals on the team.
- Co-developed and delivered training to 29 GP practices in how to help people to self-care.
- Co-developed and delivered patient training and information at selected GP practices in how people can help themselves to self-care.

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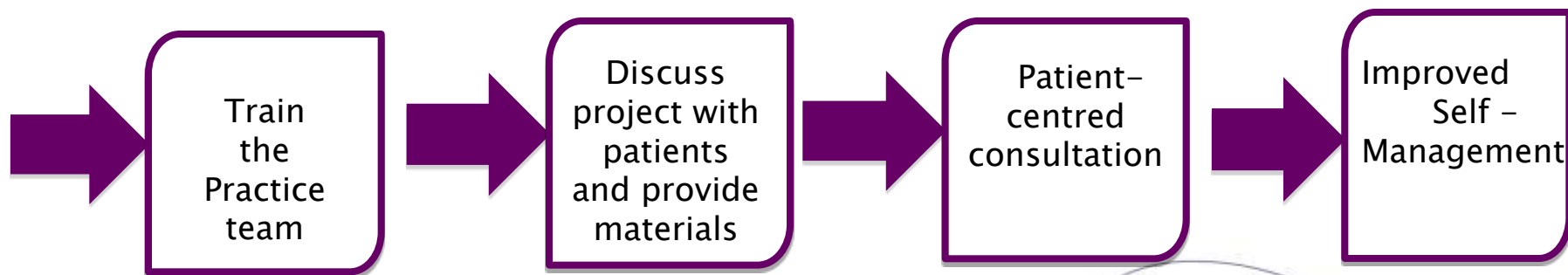
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How it worked



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About You

Thank you once again for agreeing to take part in our self-management programme. Before you start the programme, we would like to know how confident you are in undertaking certain activities regarding your condition (kidney damage). Please answer all questions as honestly as you can. The questionnaire should take approximately 5-10 minutes to complete.

For each of the following questions, please tick the box that corresponds most closely to how confident you are. 1 means not at all confident and 5 means very confident.

1 2 3 4 5

Not at all confident

Very

Information about your condition

1. I am confident that I can get information about my condition from my doctor/nurse.

1 2 3 4 5

2. I am confident that I can understand the information which my doctor/nurse gives me.

1 2 3 4 5

Communicating with doctors and nurses

3. I am confident that my doctor or nurse will be responsive and supportive.

1 2 3 4 5

4. I am confident that I can ask my doctor or nurse all sorts of questions and get meaningful answers.

1 2 3 4 5

continued...



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My Health

Please answer the following questions before your appointment (continue overleaf if necessary). Your answers will help ensure that your concerns are addressed.

1. Are you aware of the actions you can take in caring for your kidneys?

2. What is causing you the most concern about caring for your kidneys at this time?

(e.g. following a diet, taking medication, managing your blood pressure and/or diabetes, financial worries, relationships, anything else?)

3. Please write down a few words about what you find difficult or frustrating about the concern(s) you mentioned above.

4. How would you describe your thoughts or feelings about these issues?

(e.g. confused, angry, worried, anxious, worried, frustrated, stressed, fearful)

5. What would you like us to do during your visit to help address your concerns or worries?

- (Please tick the boxes in front of all that apply)*
- a. work with me to come up with a plan to address the issue
 - b. I don't expect a solution, just want you to understand what it's like for me
 - c. refer me to another health professional or other community services
 - d. other (please state):

6. I would like answers to the following questions at this visit:

7. I would like answers to these questions as soon as possible:

8. Do you have any other concerns? *(Please explain)*

Thank you



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Frequently Asked Questions

What are the kidneys?

The kidneys are a pair of bean-shaped organs located at the back of the abdomen behind the liver and intestines. They are in the small of the back, on either side of the spine.



An individual can occasionally be born with one kidney and sometimes following kidney transplantation, only one kidney is functioning. In both these circumstances, the person can lead a normal life and function equally well with one kidney if someone is born with one kidney, they may never know what a life is like.

What do the kidneys do?

The healthy kidney does a number of very important things...

- filters - removes waste, drops and toxins
- regulates - for regulating hormones, keeps the bones healthy and prevents low blood counts (anaemia)
- balances - it also balances electrolytes (salty and water) which helps maintain the correct blood pressure



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Results

- 910 patients took up self management option (69% of those asked).
- Healthcare professionals valued learning how to explain kidney disease and how to support their patients to self-care.
- People with kidney disease valued learning from others with experience – and made changes.

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Using patients to drive Quality Improvement really works

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plus notes, and
information to support
practices available.



Results to be published
early 2013 showing
measurable
improvements.

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