



PATIENT PARTICIPATION GROUP



“But I can’t manage this” Project Report March 2015

Charnwood Community Medical Group

Patients' Participation Group

'But I can't manage this'

The report of a project conducted by the PPG investigating the personal care and management of patients with long term conditions in the Charnwood Community Medical Group

Table of Contents

Preface	Page 4
Project History	Page 5
Methodology	Page 5
Analysis	Page 6
Summary of Findings	Page 9
Conclusions	Page 12
Recommendations	Page 12
Appendix 1 The Pyramid of Care	Page 14
Appendix 2 Sample Questionnaire	Page 15

Preface

The Patients' Participation Group (PPG) of the Charnwood Community Medical Group (CCMG) in Loughborough was established in February 2010 and now has a membership of twenty, representing some 12,000 patients registered with the Practice and attending one of its three medical centres in the town.

At the end of 2014 the PPG completed investigations on its two research projects – '*Accessing our surgeries*' and '*But I can't manage this*', achieving another of our aims of being a proactive group endeavouring to make a practical and positive contribution to the caring objectives of the Partners of the CCMG.

This report – '*But I can't manage this*' – focuses on our investigation of patients in the Practice who have been diagnosed with long-term illnesses. Are they managing their persistent condition well?....do they understand it ?..... or, do they need more support and care?

A sub group from the PPG have been engaged in the groundwork for this project, led by Mick Gregory supported by Margaret, Ian and Godfrey, and I am most grateful for their enthusiastic commitment to the tasks. My special thanks to Paul Hanlon, the Medical Group Business Partner, who has given so much time to encourage, support and contribute to the work.

To the Partners of CCMG... thank you for allowing us to do this project. We hope the conclusions will encourage you and your staff. In the cloud of constant criticism of the NHS, we find that the CCMG is held in very high regard by many, mindful of the high standards of care for patients that you pursue.

John Todd

PPG Chairman
March 2015

Project History

The Charnwood Community Medical Group, Patient Participation Group (PPG) commenced discussions around a project to identify if additional support for patients who have been newly diagnosed with a long term condition (LTC's) or for patients who have suffered long term illness over a long period of time was needed.

The ethos for the project came from members who had spoken with patients who had expressed some lack of knowledge about either their condition, the management of the condition or the medicines that they were taking. Additionally, there had been some national press coverage where patients were saying that they needed additional support to enable them to manage their own condition as doctors were not always providing a broad enough range of care and support.

The PPG discussed these areas and felt that a project should be established to identify if there were any patients within the Practice who required support to enable them to better manage and understand their own condition. The Practice Business Manager Mr. Paul Hanlon and Senior Partner Dr. Geoffrey Hanlon spoke to the Sub Group of the pyramid of care (Appendix 1) and how the largest group of patients approximately 1500 suffering with a LTC sit in the middle of the pyramid, and how if they don't receive adequate care and support can move upwards through the pyramid as their condition worsens.

It was recognised that this was to be a large project and would require significant research and communication with patients to identify a need for change. A project task and finish sub group was established to progress the work.

Methodology

The prevalence data for various LTC's was provided (the number of patients within the Practice who are diagnosed within each category) using this information and with the support of the Senior Partner a list of 9 LTC's was identified as being the target population for the project to be based upon.

A meeting with the West Leicestershire Clinical Commissioning Group (CCG) Proactive Care Manager and the Virtual Ward Co-ordinator was held to ascertain if there was any synergy with our proposals and the work they were undertaking. It was felt that there was and information would be shared with them at the project conclusion.

With the support of Mr. Ian Wright (an initial member of the Sub Group and former member of the PPG) a condition specific questionnaire was developed and tested using semi-structured interviews with a group of patients.

To ensure the trust of the patients and to ensure patient confidentiality no patient identifiable information (PII) was used at any stage of the project.

The questionnaire contained 11 questions with space in 3 of the questions for recipients to enter free text and a final space for any other information. The questionnaires were condition specific; however, each questionnaire asked the same questions. This enabled data analysis to be consistent against each condition. There was no space on any of the questionnaires for patients to provide identifiable information.

With the help and support of the Practice the questionnaires were sent out to all patients (within the 9 target groups) when they were invited to attend for their annual review. The letter contained information about the project and contained a pre-paid reply envelope. To ensure patient confidentiality no members of the PPG were given information regarding recipients. The planned commencement for distribution was July 2013.

A spreadsheet was developed to capture and analyse the data, each question having been given a coding for this purpose.

All entries onto the spreadsheet were double checked to look for any anomalies at the point of entry.

Using the data on the spreadsheet, pivot tables were produced against each question for analysis purposes.

The 9 identified LTC's for the project were as follows. The number in brackets shows the prevalence against each category:

- Peripheral Arterial Disease (54)
- Hypertension (1316)
- Coronary Heart Disease (373)
- Chronic Obstructive Pulmonary Disease (168)
- Chronic Kidney Disease (294)
- Diabetes (648)
- Epilepsy (82)
- Heart Failure (110)
- Stroke / TIA (228)

Analysis

Excluding the two conditions that were not progressed (discussed later) the return percentage for the project was 31.25%

Initial Question asked patients to identify their condition. The table below shows return by category of LTC.

Condition	Return	%
Peripheral Arterial Disease	20	11.18
Hypertension	26	14.53
Coronary Heart Disease	24	17.41
COPD	26	14.52
Chronic Kidney Disease	1	0.56
Diabetes	14	7.82
Epilepsy	25	13.97
Heart Failure	3	1.67
Stroke/TIA	40	22.34
Total	179	100

Question 1 asked how long it has been since their initial diagnosis

Response	Return	%
Less than 1-year	12	6.71
1 to 5-years	57	31.84
More than 5-years	103	57.54
No answer	7	3.91
Total	179	100

Question 2 Asked patients if they had ever attended a course of education to help them manage their condition more effectively?

Response	Return	%
Yes	28	15.64
No	147	82.13
No answer	4	2.23
Total	179	100

Question 3 was in two parts. **Part (a)** asked patients to identify by name any courses they had attended. There was very little detail provided for this question. **Part (b)** asked how effective the course had been.

Response (part b)	Return	%
Excellent	8	4.47
Fairly useful	17	9.50
Non useful	3	1.67
No answer	151	84.36
	179	100

Question 4 Asked if they felt more information soon after diagnosis could have helped to manage their condition better?

Response	Return	%
Yes	53	29.61
No	115	64.25
No answer	11	6.14
	179	100

Question 5 Asked patients to identify in free text any information they feel would have been useful. Please refer to page 11 for a summary of the emerged questions.

Question 6. This was a 5 part question asking patients if they were to seek information on how to manage their condition better which of the following they would prefer

A Group Course at a local Centre	Return	%
Yes	19	10.61
Might	46	25.70
No	62	34.64
No answer	52	29.05
	179	100
A one to one with your GP or Practice Nurse	Return	%
Yes	110	61.80
Might	41	23.03
No	9	5.06
No answer	18	10.11
	178	100
Internet based information	Return	%
Yes	29	16.38
Might	26	14.69
No	68	38.42
No answer	54	30.51
	177	100
Meeting with another knowledgeable patient	Return	%
Yes	23	13
Might	40	23
No	57	32
No answer	57	32
	177	100

The final section in this question asked patients if they would like to mention a method not listed above. There was little information provided in this section.

Question 7 Asked patients to identify their age range, and **Question 8** if they were male or female.

Age Range (Q7)	Return	%	Response (Q8)	Return	%
Under 20	0	0	Male	81	45.23
20 to 39	3	2	Female	93	51.97
40 to 60	31	17			
Over 60	143	80			
No answer	2	1	No Answer	5	2.80
	179	100		179	100

Question 9 asked how well you manage your condition

Response item	Frequency	%
Very well	86	48.04
Quite well	62	34.64
Not very well	14	7.82
Badly	3	1.68
No answer	14	7.82
	179	100

Question 10 asked how often do you attend the surgery for your annual review.

Response item	Frequency	%
Every year	115	64.25
Sometimes	15	8.38
Never	36	20.11
No answer	13	7.26
	179	100

Question 11 was a question asking patients to give any other information they feel appropriate in relation to education and support. Please refer to page 11 for a summary of the emerged questions.

Summary of Findings

Some of the information from the survey, for example, the age range of the majority of patients being in the over 60's and the fairly even split between male and female, was as expected. Similarly were the findings in relation to how long it has been since first diagnosis (Question 1) with the majority of patients 57.5% (103 patients) having being diagnosed over 5 years. A breakdown analysis of this question was undertaken to see if any one LTC showed any variance. Out of the 103 returns Chronic Kidney Disease and Heart Failure had a zero response and Diabetes had a response of 5. All the other conditions had a range between 23 (Epilepsy) and 12 (Peripheral Arterial Disease).

In relation to Chronic Kidney Disease (CKD) and Heart Failure (HF), these 2 conditions were included in the first wave of questionnaires sent out; however, this did present some problems and concerns from patients. Therefore for these conditions the process was halted for the following reasons. For CKD some patients were alarmed by receiving the questionnaire, this is because the LTC register within the practice identifies people who have a minimal risk of developing severe CKD and not those with it. Typically 1 in 100 will go on to develop severe CKD in their lifetime so for the majority of people there is absolutely nothing to worry about. They are however monitored using the register. For Heart Failure, it was found that many patients are on the register because they have had a one-off event. In reality this isn't really a chronic condition but does need monitoring.

Question 2 looked at those patients who had attended a course or programme of education specific to their condition 28 (15.6%) replied yes, However, 147 (82.1%) of patients answered *no*. The table below shows a breakdown of answers by condition.

Condition	Yes	No	No Answer	Grand Total
PAD	2	18		20
Hypertension	1	24	1	26
CHD	7	16	1	24
COPD	5	20	1	26
Chronic Kidney Disease	1			1
Diabetes	6	8		14
Epilepsy		25		25
Heart Failure		3		3
Stoke / TIA	6	33	1	40
Grand Total	28	147	4	179

Question 4 asked the question if patients felt that more information soon after diagnosis would have helped them manage their condition better. The table below gives a breakdown of responses by condition

Condition	Yes	No	No Answer	Grand Total
PAD	3	14	3	20
Hypertension	7	18	1	26
CHD	6	17	1	24
COPD	6	18	2	26
CKD		1		1
Diabetes	10	3	1	14
Epilepsy	9	15	1	25
Heart Failure		2	1	3
Stroke / TIA	12	27	1	40
Grand Total	53	115	11	179

Question 6 was in 4 parts asking patients if they were to seek information relating to their condition which of the following they would choose if it were available.

A group course at a local centre like your GP Surgery. This question did not show any major variance across any of the 9 LTC's, however the highest response was from patients who indicated *no* 62 patients with 19 indicating *yes* and 46 indicating *might*.

A one - to - one with their GP or Practice Nurse. The response in total against all 9 LTC's indicating *yes* was 110 with a further 41 indicating they might and 9 indicating *no*. The range for indicating *yes* was 22 for Coronary Heart disease, to 7 for Diabetes.

Internet based information. The response in total against all 9 LTC's indicating *yes* was 29 with 26 indicating *might*, however, 68 patients responded with a *no*. The range for indicating *yes* was 7 for Hypertension and *no responses* for Chronic Kidney Disease and Heart Failure.

Meeting with another knowledgeable patient. The response in total against all 9 LTC's indicating *yes* was 23 with 40 indicating *might* and 57 indicating *no*. The range for indicating *yes* was 8 for Coronary Heart Disease to *no responses* for Heart Failure and Chronic Kidney Disease.

Question 9 asked how well patients thought they managed their condition. The response to this question did not show any major variance against any one condition. However Heart Failure and Chronic Kidney disease did show a low return. This is thought to be in the main caused by their lower prevalence. Combining the total of patients who replied that they managed their condition *very well* or *quite well* was 148 with patients saying that they managed their condition *not very well* or *badly* was 17.

Question 10 asked how often patients attended the surgery for their annual review. The table below shows the response by condition.

Condition	Every year	Sometimes	Never	No Answer	Grand Total
PAD	10	3	5	2	20
Hypertension	17	3	5	1	26
CHD	20	1	2	1	24
COPD	18	1	4	3	26
CKD			1		1
Diabetes	12	1		1	14
Epilepsy	19	2	2	2	25
Heart failure	3				3
Stroke / TIA	16	4	17	3	40
Grand Total	115	15	36	13	179

From the questions where patients could comment in their own words, an analysis has been undertaken. These answers have been formulated into a series of emerged themes that patients would like to know.

Prognosis

- What does my diagnosis mean?
- How did it happen?
- How serious is it?
- How will it affect my future, both immediate and long term?
- Can I control it (a) to keep it stable and (b) to avoid further problems?
- Will I need regular monitoring, tests etc. ?

Education

- Where can I learn more, courses, costs, leaflets, booklets, support groups?

How will it affect my family life?

- Will it affect my work and do I need to inform my boss?

Medication.

- What are my tablets for, and are there any side effects?
- Will I need to take them for the rest of my life?
- If I have a cold or flu etc. What other medication can I take safely?

Aids and helpful equipment.

- How and where can I get them e.g. walking frame, wheelchair?

Diet.

- How does my diet need to change
- What are the right and wrong foods for me to have to control my sugar levels correctly (diabetes)?

Alcohol.

- Can I still have a drink?
- Will it affect my medication?

Leisure and exercise.

- Can I still drive, do I need to inform the DVLA?
- Can I still Cycle?
- Can I continue to swim?
- Can I still go boating??
- What about flying can I still go abroad, do I need to inform my travel insurance company?
- Will it affect my life insurance and do I need to let them know?
- What safe exercise can the elderly do at home?

Financial Help.

- Where can I get some advice from?

Conclusions

The findings from the survey give some interesting information.

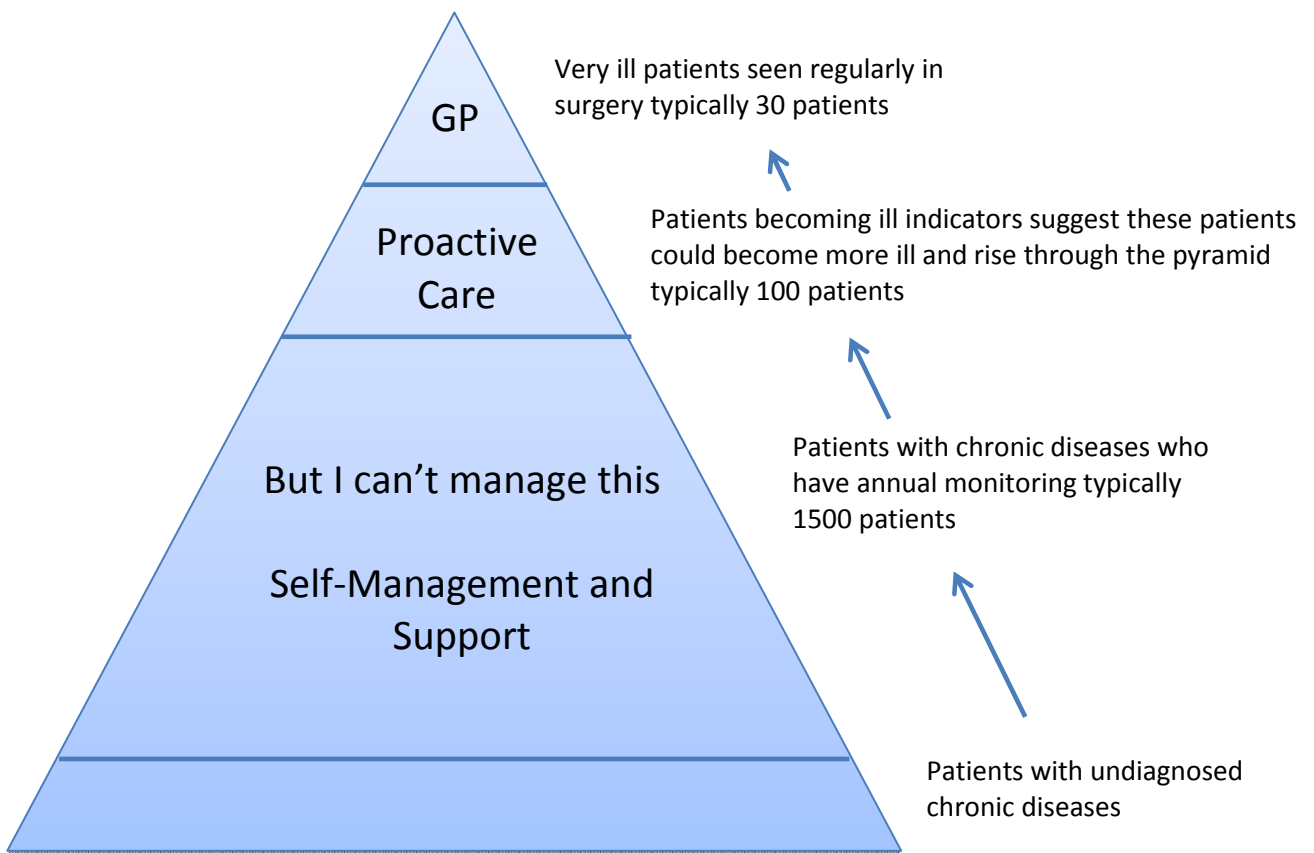
- Responses showed that those who had attended a course or programme of education found it to be excellent or fairly useful. However, the largest response from patients showed that they had not attended a course or programme, and further showed that 34.6% of patients would not want to attend a group course. It was felt that this may be down to the age profile of many of the patients.
- In relation to obtaining information regarding their condition, 68.4% of patients (excluding no responses) show that patients do not want any additional information soon after their diagnosis. This level of response needs some further work to identify the reasons for this.
- In relation to the above points the survey did however show, that given a choice of options for obtaining information that would allow them to manage their condition better, that 68.75% of patients (excluding no responses) would prefer a one- to- one with their GP or Practice Nurse.
- Again probably due to the age demographics of the survey population the majority of patients would not wish to access the internet for additional information.
- Probably due to the age profile within the survey population, a high percentage of patients (47.5%) would not wish to meet with another knowledgeable patient to obtain information regarding their condition to help them manage better.
- Pleasingly the survey does show in question 9 that 148 patients (nearly 90%), excluding the no responses feel that they are managing their condition very well or quite well.
- Another encouraging indicator from the survey shows that 115 patients (69%) excluding the no responses attend for their annual review every year. However, a further 51 (almost 31%) excluding the no responses sometimes or never attend. Further work will be needed in this area to ascertain the reasons and to prevent this group of patients moving higher through the pyramid of care and neglecting their personal care.

Recommendations

- Look at reasons why patients do not want additional information regarding their condition at the time of initial diagnosis. Look at the available information leaflets and produce a list of questions that GP's may ask patients.
- As the highest percentage of patients would prefer a one- to- one with their GP or Practice Nurse, consider ways that this can be achieved, including discussions with West Leicestershire Clinical Commissioning Group. Consider including in the annual review invite letter a statement recommending patients to ask questions when they see their GP or Nurse. Produce a list of prompt questions that GP's could ask the patient. Review the information leaflets available.
- Look at the reasons why patients do not attend their annual review (in spite of the fact that they receive 3 invites). Produce a statement for the letter stating the significance of attending.

- Looking at the responses from the questions asked it is clear that there are patients with concerns and uncertainty regarding their condition and how it affects them. Consideration should be given to the production of a leaflet summarising frequently asked questions.

The information from the survey does show some areas where further investigation could be worthwhile, it does however show that patients in the Practice are benefitting from the support and clinical care already being given by the Charnwood Community Medical Group. This is evidenced by the high positive responses to the survey questions from the number of patients attending for their annual review and also by the high numbers of patients who say that they are managing their condition very well or quite well. The Practice is congratulated on these findings.



Appendix 1 The Pyramid of Care

Appendix 2 Sample Questionnaire Patient Survey - Diabetes.



Even if you have more than one long-term illness, we would like you to answer the following questions with regard to your diabetes.

1. How long is it since your diabetes was diagnosed? Please tick one box.

Less than one year One to five years More than five years

2. Have you ever attended a course to help you (and perhaps a partner) manage your diabetes more effectively? Please tick one box.

Yes No

3. If you answered "No" to the last question please go straight to question 4. If you answered "Yes" please tell us the name and date of the course and where it was delivered. Use the box below for your answer.

How do you rate the course in helping you to manage your diabetes? Please tick one box.

Excellent Fairly useful Not useful

4. Do you feel that more information soon after diagnosis could have helped you (and perhaps a partner) to manage your diabetes better? Please tick one box.

Yes No

5. If you answered "Yes" to the last question, what sort of information would have been valuable to you? Please write in the box below. If you answered "No" to the last question please go to question 6. If you need more space please use the box on the back of this sheet.

6. If you (or a partner) were to seek information on how to manage your diabetes better, which of the following would you consider using if it was available? For each of the methods (A to D) listed below tick "Yes", "Might" or "No" to indicate whether you would consider using it.

	Yes	Might	No
A. A course or group-meeting at a local centre (like your surgery or community centre):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. One-to-one with your Doctor or Practice Nurse:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Internet based information:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Meeting with another knowledgeable patient who was approved by your Doctor:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. If you would like to suggest a method not listed above, please describe it in the box overleaf.			

7. Which age range do you fit into? Under 20 20 to 39 40 to 60 Over 60

8. Are you male or female? Male Female

9. How well do you manage your diabetes? Very well Quite well. Not very well. Badly

10. Do you attend the surgery for diabetes annual review? Every year Sometimes Never

If you would like to provide any additional comments on patient education please use the box on the back of this form.

(REVERSE OF FORM)

If you would like to add any comments on how the education of patients with long-term illness could be improved, please write them here:

**Pease return this questionnaire to the surgery in the enclosed postage paid envelope
or hand it to reception at your annual review.**

Thank you for helping us with this important survey.