Personalised care planning for long-term conditions

Rosie Walker, Jill Rodgers

Personalised care planning (PCP) is recommended in national health policy for the annual review in the care of people with diabetes or other long-term conditions. PCP is a process that engages and involves people with long-term conditions in decisionmaking about their condition, including sharing results before the annual review consultation, making the consultation experience truly collaborative, and prioritising the goals of the person with the long-term condition in creating a joint action plan. Many practices have already implemented PCP, but for many others questions and concerns remain. This article directly addresses these and provides sources of evidence and information to help practitioners feel more confident about developing this approach.

Personalised care planning (PCP) is the recommended approach to the annual review for people with diabetes or other long-term conditions in the NHS (Department of Health [DH], 2010a; Mathers et al, 2011; NICE, 2011). The benefits of PCP in addressing satisfaction with services as well as promoting confident self-management of long-term conditions have been demonstrated, alongside many other advantages, such as improving attendance rates and healthcare professional (HCP) enthusiasm for delivering services (Diabetes UK et al, 2011; Walker et al, 2012).

Personalised approaches have been advocated in health policy over the past decade and continue to form a central part of the Coalition Government's NHS reforms for England (DH, 2010b) and in the other UK nations (Welsh Assembly Government, 2002; Scottish Government Health Delivery Directorate Improvement and Support Team, 2010; Northern Ireland Department of Health, Social Services and Public Safety, 2011). *Box 1* outlines the recommended process for PCP and *Box 2* shows what a PCP consultation looks like in practice.

Despite widespread recommendation of the PCP approach and clear information about the process (NHS Diabetes, 2008), there remains some uncertainty and confusion about what PCP means in practice and how it can be implemented. From the authors' knowledge of the evolution of PCP, responses to their publications aimed at helping people to understand it better (NHS Diabetes, 2008; Walker, 2008a; 2008b; Walker and Akroyd, 2008; Walker and Rodgers, 2011) and their extensive experience of providing skills-based workshops in the PCP approach, it is clear to them that questions and concerns remain.

This article highlights the questions the authors are most often asked, and the concerns most

Article points

- Personalised care planning (PCP) is the recommended approach to the annual review of people with diabetes or other long-term conditions.
- PCP engages and involves people with long-term conditions in decisionmaking about their condition.
- 3. However, many healthcare professionals (HCPs) are still uncertain about what PCP means in practice and how it can be implemented.
- 4. This article addresses the main concerns and questions raised by HCPs.
- 5. It is hoped that by addressing these, PCP will be more readily implemented, to the benefit of people with long-term conditions.

Key words

- Annual review
- Long-term conditions
- Personalised care planning
- Results sharing

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Box 1. Stages of personalised care planning (PCP).

- **Stage 1:** Awareness-raising of what to expect from the PCP approach and its underlying principles (for staff as well as people with long-term conditions).
- Stage 2: Appointment 1: to have relevant tests and investigations carried out, such as blood tests, blood pressure and foot examinations.
- Stage 3: The results, as well as an objective explanation of their meaning, are made available to the person with the condition. An invitation to reflect on the results, and think about their most pressing concerns in advance of the PCP consultation, is included with the results.
- **Stage 4:** Appointment 2: the PCP consultation a collaborative discussion of the person's results, their goal setting and joint action planning, including arrangements for further review (*Box 2*).
- **Stage 5:** Future appointments: prioritising the review and evaluation of the action plan, and creating further action plans.

Box 2. The personalised care planning consultation.

- The views of the healthcare professional (HCP) and the person with a long-term condition are seen as equally important and valid.
- There is a joint discussion of the concerns and priorities raised by the results, and of the person's reflections in advance of the consultation (this may include physical, emotional and social aspects).
- Goal setting, resulting in the person's own goal being recorded.
- Action planning, resulting in actions towards the goal for both the person with a long-term condition and the HCP.
- Plans for review and ongoing support.

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- The skills associated with collaboration in formulating the care plan in the personalised care planning approach are very different from those required in the more traditional setting.
- 2. Particular skills that are needed to consult in this way include asking open questions, paraphrasing, summarising and attentive body language.

often raised, together with their responses. They hope that these will illuminate the approach for the reader and help to bring PCP to services more easily so that people living with long-term conditions can be more involved in their own care.

Frequently asked questions

Q: We've always done care plans, ever since training days. What's new?

This is right. The terminology does have a familiar ring to it. Anyone who trained in a hospital setting will be accustomed to the care plan - a plan formulated by staff for looking after someone who could not do it for him- or herself, because of illness. This can work well in

an acute setting where staff are in charge, taking the decisions and temporarily being responsible for the person's health and wellbeing.

The PCP approach addresses the reality that the majority of people with long-term conditions are not in a hospital bed, but are living their lives independently. What the PCP model emphasises is the activity of creating the care plan ("the verb, not the noun" as it has been described). This involves the person with the long-term condition in decision-making as much as, if not more than, the HCP. For example, the individuals might choose for themselves which of their results they wish to focus on or what strategy to use for losing weight. The skills associated with collaboration in formulating the care plan in this approach are very different from those required in the more traditional setting, and that is why our familiar context for a care plan cannot easily be transferred. We need to learn to do "old things in new ways". Particular skills that are needed to consult in this way include asking open questions, paraphrasing, summarising and attentive body language (Walker, 2000).

Q: Do we have to implement all the PCP stages? (*Box 1*)

In short, yes, since the whole rationale behind PCP is that the person with the long-term condition is an equal partner in the process and the decisions that are made about his or her condition. The central tenet behind each stage is that the person with the long-term condition knows as much as the HCP about his or her health and the system of care to expect.

The stages, particularly results sharing and opportunity for the person to reflect on his or her priorities, also give people greater confidence to participate more during a consultation, rather than being passive. Many services that have already implemented the PCP stages have found that they can build on their existing systems and processes rather than create new ones.

Q: How do you encourage people to attend two appointments? We have enough trouble with missed appointments as it is.

People will make an effort to engage in something that is personally meaningful to

them. Much non-attendance occurs because people simply do not see the point of attending – especially when they feel essentially well or that they might get a telling-off (Snow and Fulop, 2012). Attending twice might need more effort, but what people get out of it is not only some meaningful results (their own), but also time to think about them. They are also able to have a discussion with the HCP that is not interrupted by clinical tests and examinations being carried out.

Where PCP has been implemented, both staff and people with long-term conditions have reported it to be a much better use of their time and effort (Duquemin, 2011). The authors have heard more than once that people who have frequently missed appointments start to attend regularly again. They have also found that if the process is explained and people with longterm conditions are fully prepared for it, they are very willing to participate, and this is borne out in the literature (Diabetes UK et al, 2011; Walker et al, 2012).

Q: Where will we find the resources to reorganise all our clinics in the face of NHS cuts?

Like any new system, it takes time and commitment to implement PCP. It may need a change in roles within the multidisciplinary team, and changes to administrative systems and clinic timings, but once these are in place PCP takes no more time than using a traditional system; indeed, in many instances time savings have been made by reducing duplication (Diabetes UK et al, 2011; Duquemin, 2011).

As stated earlier, wholesale reorganisation is not always necessary, as existing systems can be adjusted and developed. For example, many people with long-term conditions already have blood taken for testing before their annual review appointment, and in many places where PCP has been implemented this visit has been extended to include other tests and examinations. Our experience is that taking the opportunity to reflect and plan for such developments is both valuable and inspiring (Walker and Rodgers, 2011).

Q: How can we provide an explanation of the results that everyone can understand?

There are ready-made examples of explanations of results that can be used (NHS Diabetes, 2008; Walker and Rodgers, 2011), or readers may wish to develop their own. The most important aspect is that the explanation is objective, such as "a blood pressure of below X has been shown to reduce the risk of circulatory problems," rather than "your blood pressure is higher than normal."

Providing the information as recommended ranges that reduce future risk can help people to decide for themselves whether they are comfortable with their own readings: this is an important step in deciding what actions they will take in response. Because "one size doesn't fit all", you will need to present the results according to your local population needs and in line with your practice computer system.

Q: What if people don't want their results in advance?

Implementation of PCP across varied populations has shown to date that the majority of people welcome their results, even in situations where their HCP has feared they may not (Hong et al, 2010; Walker et al, 2012).

You won't know until you try it, but our recommendation is not to pre-judge whether someone will welcome their results. Instead, give them the opportunity of reviewing them and then have a conversation to find out whether they thought it was helpful. Some may say it was not, and some may choose not to read the results in advance, but the important thing is that everyone is given the choice and opportunity.

Even if people do not want to access their results, the invitation to actively reflect on priorities in preparation for the PCP consultation remains an important part of encouraging greater participation in, and equal contribution to, the consultation (Walker and Rodgers, 2011).

Q: What if people don't understand their results and worry excessively before their appointment?

Most people have some concerns before they attend a consultation, whether they have had

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- Wholesale reorganisation is not always necessary, as existing systems can be adjusted and developed.
- 2. There are ready-made examples of explanations of results that can be used, or readers may wish to develop their own.
- 3. The explanation of results must be objective, such as "a blood pressure of below X has been shown to reduce the risk of circulatory problems," rather than "your blood pressure is higher than normal."
- 4. Providing the information as recommended ranges that reduce future risk can help people decide whether they are comfortable with their own readings, and hence what actions they will take in response.
- 5. Implementation of PCP across varied populations has shown that most people welcome their results, even in situations where their healthcare professional has feared they may not.

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- 1. The main worry of many people with a long-term condition is "not knowing what they are going to be told": having results in advance so that they can reflect on the reality, rather than their fears, is therefore a useful step.
- Explaining the changes to the system in advance, reinforcing that information at the first appointment and explaining the results as clearly as possible will all help to reduce the chance of excessive worrying.
- 3. Prioritising the concerns of the person with the long-term condition is far more likely to result in behaviour change than the more traditional method where the HCP was in charge of the agenda.
- 4. Once the system is in place and everyone is familiar with it, overall consultation time is reduced, as people are more satisfied, better able to self-manage and, as a result, likely to need a smaller number of consultations overall.

access to their results in advance or not. These include worries such as being given bad news that complications are developing or being told off for results that fall outside the recommended range. For many people, their main worry is "not knowing what they are going to be told." On this basis, having results in advance so that they can reflect on the reality rather than their fears is a useful step.

Explaining the changes to the system in advance, reinforcing that information at the first appointment and making the explanation of the results as clear as possible will all go a long way towards reducing the chances of excessive worrying.

Q: Won't the consultation take up much more time if there's so much to go through?

HCPs using this approach have found that having a PCP consultation where *all* the time can be used to discuss and share important issues, rather than also trying to perform clinical examinations and explain results, means that time is used much more efficiently (NHS Diabetes, 2008; Diabetes UK et al, 2011).

A consultation style that encourages people to voice their main concern about living with diabetes and to consider their own options for dealing with it before choosing themselves which to try is far more likely to result in behaviour change than the more traditional method of the HCP being in charge of the agenda.

Once the system is in place and everyone is familiar with it, overall consultation time is reduced, as people are more satisfied, better able to self-manage and, as a result, likely to need a smaller number of consultations overall (Diabetes UK et al, 2011).

Concerns

I don't think the patients in our practice will like it.

It is quite easy to make this assumption, especially when you have known people for many years and have got used to relating to each other in a certain way. But in reality, the only way to find out whether people like this system is to introduce it to them and evaluate the experience. Many services using the PCP approach introduced it first as a short-term pilot, so that they could gauge its effect for themselves. Fortunately, there is published evidence of its acceptability among people with long-term conditions, from a variety of practices (Hong et al, 2010; Diabetes UK et al, 2011; Walker et al, 2012).

Some people expect to be given advice – they say "you're the expert, tell me what to do."

This response is borne out of the traditional medical model, which most of us – patients and HCPs alike – have come to expect. If you wanted to analyse how to respond to the request to "tell people what to do," we would ask you to consider the extent to which people follow the advice you subsequently give in this situation. If people always do as you tell them, then carrying on with this approach may be worthwhile; if not, it may be that a new approach would yield more effective outcomes.

There is a lot of evidence that people do not simply do as they are told, especially when living with a long-term condition, and need a different approach to enable them to experience success (Myers and Abraham, 2005; Knight et al, 2006; De Silva, 2011).

This is just the latest reform – next week it will be something else and we'll have made all those changes for nothing.

The current recommendations bring together a body of evidence for interventions that have been shown to be effective in the management of long-term conditions. This area has been receiving increasing attention for the past few decades, as the burden of long-term conditions has been steadily rising along with the recognition that the traditional paternalistic approach does not fit with living with an essentially self-managed condition. It is highly unlikely that in future a less personalised approach will be advocated.

I don't think I have the right skills to do all that listening – if I'd wanted to be a counsellor, I would have trained as one.

PCP does represent a new way of working, and for many it also means a move out of

their consultation "comfort zone". Changing our own practice as HCPs can take as much effort as someone with diabetes changing their lifestyle. Recognising that you may need to develop different skills for this evidence-based approach, just as you would for any other medical development, is important.

To start the process of change, one useful question for readers to ask themselves is "how effective is my current consultation style for people with long-term conditions?" Finding out about the areas of personal concern and working on those areas, can lead to a more fulfilling experience in consultations; there are many sources of information and inspiration to provide support in developing the skills (Anderson and Funnell, 2005; NHS Diabetes, 2008; Diabetes UK, 2009; Successful Diabetes, 2010; Mathers et al, 2011; NHS Diabetes, 2012). By far the easiest and quickest way of listening more effectively, that we know of, is to stop talking!

Concluding remark

The phrase "no decision about me, without me" (DH, 2010b) underpins current health policy, and PCP is the embodiment of this principle. The authors' hope is that by addressing the concerns and questions outlined here, HCPs will be helped to implement PCP more readily, to the benefit of people with long-term conditions nationwide.

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Page points

- Changing our own practice as HCPs can take as much effort as changing their lifestyle does for a person with diabetes.
- You may need to develop different skills for this evidence-based approach, just as you would for any other medical development.
- Finding out about areas that concern you, and working on those areas, can lead you to a more fulfilling experience in consultations.
- 4. By far the easiest and quickest way of listening more effectively, that we know of, is to stop talking!