

# The value of patient support programmes

## Who should read this briefing

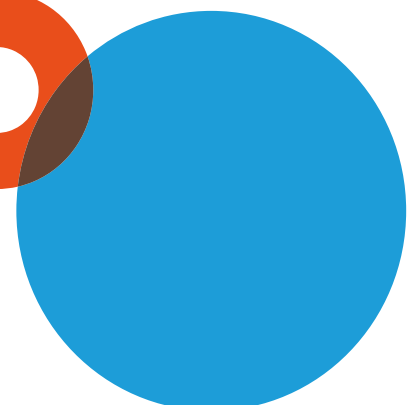
- This briefing is for those involved in the commissioning or provision of care to patients with long-term conditions.

## What this briefing is for

- To explain what patient support programmes are for, explore some of the barriers to greater use of them for NHS patients with long-term or chronic conditions and look at what action is needed to overcome these with the aim of encouraging more decision makers to consider whether they could contribute to improved and more personalised care of patients.

## Key points

- Lack of awareness among both healthcare professionals and patients is a key barrier to the increased uptake of patient support programmes (PSPs). Improving knowledge, for example around their regulation, could mean healthcare professionals are more willing to recommend them.
- A better developed evidence base for PSPs would help acceptance. Some of this could be from existing sources such as patient reviews or from patient-reported measures, but evidence around financial benefits would also help.
- While PSPs often come at no additional cost to the NHS, the savings from better outcomes from medication may not be visible to everyone in the system and may accrue in other parts of it.
- Shared information accessible to all those involved in the patient's care could help develop understanding of PSPs and their benefits. This is not always easy at the moment.
- There are opportunities for PSPs to link into wider movements, such as towards more personalised care or community prescribing, which ought to be exploited.



Offering personalised care will be a key task for the NHS in the next decade. It will recognise that patients with the same condition have different needs, and seek to meet those.

Doing this effectively and within a limited budget will not be easy. But there are partners willing to help the NHS in this, including pharmaceutical companies who offer patient support programmes (PSPs). These assist individual patients taking specific medicines by offering tailored support, often at no additional cost to the NHS. However, awareness of these programmes is low and they are not being used to their full potential.

The NHS Confederation brought together a range of stakeholders to identify barriers to the increased uptake of PSPs, discuss what could be done to overcome them and the potential benefits for the NHS.

**“It will recognise that patients with the same condition have different needs, and seek to meet those.”**

Providing care tailored to the individual receiving it will be one of the big challenges for the NHS over the next decade. It has long been recognised that a ‘one size fits all’ approach will not necessarily get the best outcomes for the patient and for diverse communities, and potentially will cost more.

While it may be lifesaving to have a standardised approach to a patient in cardiac arrest, the need for more individualised approaches is clear in the treatment and management of chronic diseases, where people may be taking medications for a lifetime.

Offering the care each individual needs may also help the NHS to cope with the expected rise in the number of patients with long-term conditions and ensure they are treated closer to home, whenever possible.

Enabling patients to manage conditions at home with support from localised NHS services, and thus minimising their need to be admitted to hospital, has been a key part of the NHS’s plans both in the Five Year Forward View (in 2014) and now the ten-year plan.

As the proportion of the population with long-term conditions increases, this need may become more pressing. Currently there are over 15m people in England with one or more long-term conditions but that number is growing and, within it, an increasing proportion have multi-morbidities.

Care for those with long-term conditions dominates the NHS. The House of Commons health select committee found they account for:

- 55 per cent of GP appointments
- 68 per cent of outpatient and A&E appointments
- 77 per cent of inpatient bed days.

But self-management often involves input from the NHS upfront, helping patients understand what they need to do to stay as healthy as possible, informing them of the likely effects and side-effects of treatment, and ensuring they have individualised support if problems develop.

There has been significant progress in enabling some patient groups to self-manage in this way, but it is

not universal across the range of chronic diseases. Financial constraints can play a part in this, as can the complexity of the condition, its treatments and the type of patients most likely to be affected. Some patients may feel daunted by the prospect of self-management and need additional support which the NHS may struggle to provide at the moment.

A number of healthcare providers and pharmaceutical companies have developed an answer to some of these challenges in the form of patient support programmes (PSPs), which deliver services supplementary to those of the NHS and aimed at improving patients' ability to manage their care more effectively. These are often funded by the companies themselves at no cost to the NHS or the patient. PSPs are normally paid for by pharmaceutical companies but the service is delivered by a third party, so the pharmaceutical company has no direct contact with the patient.

While the package of care on offer may differ from condition to condition, and from company to company, they can include:

- ensuring a reliable supply chain leads to timely home delivery of patient medications
- training on effective self-medication and administration of medicines, which may be much more complex than simply taking a pill twice a day.
- information on appropriate management pitched at a level suited to the patient
- motivational training to improve adherence to medication regimes. Some medications take a long time to show benefits and patients need to be encouraged to continue.
- telephone hotlines, including out of hours, to access advice from qualified healthcare professionals.

The level of support to the patient is very much based on their individual position and what support they need and want to access. In some PSPs, peer mentors will be used to help patients overcome challenges in adherence.

As the NHS faces ever tighter budgets and is desperately short of staff, PSPs may offer an opportunity to reduce

pressure on parts of the service while improving care for patients. But what are the barriers and solutions to making their use more widespread?

**“PSPs may offer an opportunity to reduce pressure on parts of the service while improving care for patients.”**



# Barriers to wider use of PSPs

## Knowledge and understanding of PSPs

One of the most fundamental barriers to PSPs is a lack of knowledge and understanding of them among NHS staff in particular. We know that even now, in a technologically-driven information age, patients trust medical professionals more than other professions. This trust and reliance on them is still high and has continued even though shared decision-making has grown in importance. This means that PSPs are unlikely to be recommended to or asked for by patients and those around them simply because neither healthcare professionals nor patients know they exist.

NHS staff and others who are aware of them may have scant knowledge of how they work and their benefits. In particular, it may not be well known that PSPs are provided free of charge to both the NHS and to patients, and have the potential to reduce other costs if patients call the helpline rather than going to their GP, hospital or A&E.

There is also confusion about what is meant by the term patient support programme and the possibility of confusion with other programmes, and therefore a misunderstanding of what PSPs can offer. Many other support programmes will not focus on particular products in the same way as PSPs and may be more generic.

**“It may not be well known that PSPs are provided free of charge to both the NHS and to patients, and have the potential to reduce other costs.”**

This confusion can extend into other terms such as ‘home care’, which is often provided as part of a PSP and may have a different meaning to those working in social care and around the NHS.

Many NHS staff will not realise that patient support programmes are highly regulated and governed.

This could affect their willingness to refer patients to them, as non-regulation is a key referral barrier for clinicians. The National Homecare Medicines Committee oversees PSPs. It is part of the NHS’s Specialist Pharmacy Service and there is a standard contract in place across the NHS. In addition, the pharmaceutical companies have to work within robust guidelines laid down by the Association of the British Pharmaceutical Industry. This level of regulation could offer reassurance to the NHS about how PSPs operate.

## Fitting into the infrastructure of the NHS

PSPs potentially impact on many parts of the NHS but don’t have an automatic ‘home’ in the current infrastructure of the NHS.

Many patients will first encounter PSPs after they have been in contact with secondary care services and have been prescribed a particular medicine, but much of their ongoing care may be provided by community teams or through their GP practice. However, many of the patients who are receiving a PSP also have other conditions and may be in contact with other parts of the NHS about these.

Lack of communication between the different parts of the service is a known problem, with patients often not receiving a joined-up service. How PSPs then interact with these different parts of the system is a challenge. Where there are benefits as a result of PSPs, such as avoiding admissions, they may not be obvious to all parts of the system and any financial benefits will not be shared due to the silo nature of NHS funding.

## Information sharing

As PSPs are provided by non-NHS bodies there are issues around sharing data, which has to be done with the patient’s consent. Where this is held electronically, there may also be technical problems about how this could be shared and incorporated into the patient’s records.

Sharing information would be one way to boost the visibility of PSPs and make the NHS aware of their benefits. It could also allow greater coordination, allowing NHS staff to request greater support if a patient was struggling with adherence or information

# Solutions

about the patient held by the PSP provider to be summarised for the NHS staff involved in their care.

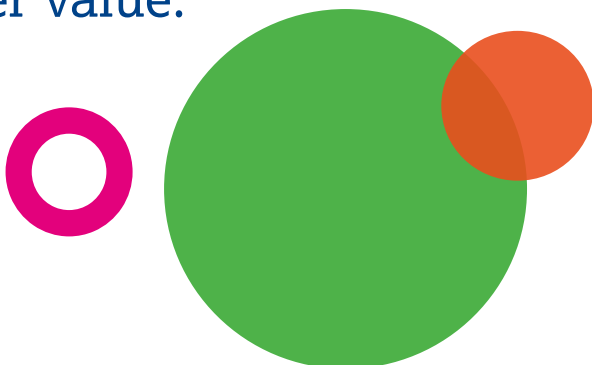
## Reluctance to get too close to pharmaceutical companies

In some parts of the NHS there is a reluctance to be seen to be working too closely with pharmaceutical companies and a suspicion about their motives in doing work or providing services. This can affect 'buy in' to value-based programmes such as PSPs even when there is no direct cost to the NHS and they are provided as an unpaid service to patients. Ways to increase uptake of this service may be as simple as emphasising that they make the medicines the NHS does pay for work better and therefore deliver better value.

## Access to the underlying medication

PSPs are specific to the medication a patient has been prescribed and are therefore only available to patients while they are on certain medications, even if elements of the PSP offer would be useful at other points in their patient journey or to other patients. This can mean access to PSPs is very dependent on the use of the underlying medication, which may be restricted or just not favoured by some clinicians.

**“Ways to increase uptake of this service may be as simple as emphasising that they make the medicines the NHS does pay for work better and therefore deliver better value.”**



## Promote understanding of the role of PSPs

For the NHS, the PSP may be a useful tool in the armoury to tackle long-term conditions, improve patient experience and reduce the overall cost to the system. But, that requires greater understanding of what PSPs are and what they can do. Greater knowledge and understanding of them could help break down some of the concerns about the involvement of pharmaceutical companies.

Patients probably know little about PSPs until they are receiving one. More active, informed and engaged patients could help their spread by questioning why they are not receiving this level of support. The role of communities and patient-led support agencies in advancing the use of well-reviewed PSPs should not be underestimated.

## Develop an evidence base for the impact of PSPs

Arguments for increasing use of PSPs would be bolstered by an evidence base showing their benefits for the NHS and for the patients who access them. These benefits might include improved adherence to medications and better outcomes for the patients, using both clinical indicators and patient reported measures. Existing evidence could include reviews on websites such as I Want Great Care.

Other areas that could be looked at would include PSPs' contribution to greater patient activation, using recognised measures of this and greater community engagement in decision-making about local services. This could recognise that PSPs may have spillover effects and impact on how patients look after their health and engage with services more generally.

Such an evidence base is likely to draw on the experience of NHS staff with patients in PSP schemes who may see the outcomes of these. Specialist nurses may be the staff who see the value of PSPs most, as they are well placed to see the impact on patients. Consultants may not see or be aware of the impact in the same way. Sharing relevant information between multi-disciplinary healthcare professionals could be key.

## Understanding costs and benefits

There are some obvious benefits to the NHS of PSPs. First of all, they may be doing work that would

otherwise either be picked up by NHS staff or left undone, to the detriment of the patient. Patients who adhere to medication regimes may be less likely to need or seek care from GPs or hospitals, and may need less input from community nurses. In some cases, PSPs may prevent expensive hospital admissions.

If patients take their medication correctly and adhere to the regime, the NHS is more likely to get full value from what are expensive medicines. This links into the Getting it Right First Time agenda. 'Monetarising' these benefits would help to make a case for PSPs.

While these potential savings are relatively easy to cost, there are other benefits which largely accrue to patients. These may be improved outcomes in terms of the primary condition they have, or a reduction in stress and anxiety if they know help is available, such as through a telephone helpline.

PSPs come at no extra cost to the NHS, but the benefits are rarely costed or quantified in a way that would make the case for PSPs compelling. Such costing can present challenges but could provide a helpful way for PSPs to be recognised and increased, especially as the NHS is now very obviously struggling with the resources available.

**“While potential savings are relatively easy to cost, there are other benefits which largely accrue to patients. These may be improved outcomes in terms of the primary condition they have, or a reduction in stress and anxiety.”**

### **Being seen as part of a wider movement and linking into this**

The NHS is looking to provide person-centred care: PSPs fit within the ethos of this with their focus on tailored help for the individual and those around them who may be involved with medicines administration and adherence. The emphasis on empowering people to live with and manage their long-term conditions also resonates with key NHS aims. PSPs should try to be seen as part of a plurality of interventions aimed at improving patient experience and empowerment.

PSPs could also link with community prescribing, which is a deeper and more community-led approach than social prescribing, where an alliance of community providers work with GPs to deliver services. In some communities there had been resistance to social prescribing as it was seen as outsourcing financial problems. However, this opposition vanished when the community was engaged in developing a new model of community prescribing. Public and patient engagement of diverse communities in designing care could produce more effective schemes because it would improve take up and adherence.

### **Working with those with responsibility for coordinating care**

The NHS has many initiatives aimed at improving care for people with long-term conditions. In some areas, Primary Care Home – which works across communities of 30,000 to 50,000 people – acts as mechanism to drive personalisation of care. In others, multispecialty community providers link GP practices, trusts and other services. Linking into these could help PSPs become more mainstream.

However, the landscape of the NHS is changing rapidly and new bodies and ways of working are emerging that could help PSPs become a recognised and valued part of the wider system, and potentially develop at scale.

The development of more integrated ways of working is aimed at creating a more joined-up, seamless service for patients that also reacts to patients at an earlier stage in their condition – or even before conditions develop. The prevention of expensive

# Conclusion

hospital stays through early intervention ties in with the ideas behind PSPs, with the focus on providing help when the patient feels they need it rather than letting problems become a crisis.

**“The landscape of the NHS is changing rapidly and new bodies and ways of working are emerging that could help PSPs become a recognised and valued part of the wider system.”**

Improvement methods could be needed to spread some of this best practice and improve care for those with long-term conditions. Creating a seamless well-performing service can be easier if certain factors are in place. Shared geographical boundaries between local authorities and NHS bodies are helpful, and there is evidence that NHS leaders with a long tenure are also associated with better performance. Real community engagement is also required, where partnerships develop with patients and people providing services.

PSPs will need to link into the models that do emerge and to have contact with those organising a personalised package of care around the patient so that they are embedded in the care plan.

## Link to health inequalities

Health inequalities are high on the agenda for many in the NHS. PSPs can improve treatment for people who may be affected by health inequalities, for example, because they live some distance from hospital and would find it difficult to attend training or seek help there. More widespread use of them could potentially even out some of the differences in the care received by patients.

## What you can do

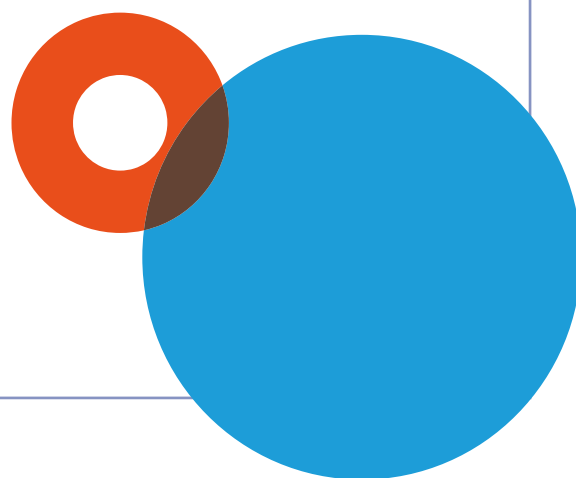
1. **Consider whether patient support programmes could contribute to the care of patients in your organisation**, perhaps identifying groups of patients with chronic conditions who could benefit from them.
2. **Talk to potential partners in the pharmaceutical industry** about what would be available to these groups.
3. **Look at how such schemes could be introduced and who would need to be involved** or consulted to make this happen.



## Thanks and acknowledgements

We extend our thanks to the participants of the roundtable discussion for their insight and valuable contributions that have informed this paper. The roundtable was hosted by the NHS Confederation in partnership with AbbVie and was attended by senior leaders from the following organisations:

- AbbVie
- NHS Confederation
- NHS England
- Health Foundation
- NHS Newham CCG
- King's College Hospital Foundation Trust
- ReThink Mental Illness



If you require further copies of this publication or to have it in an alternative format, please contact [enquiries@nhsconfed.org](mailto:enquiries@nhsconfed.org). We consider requests on an individual basis.

©NHS Confederation 2018. You may copy or distribute this work, but you must give the author credit, you may not use it for commercial purposes, and you may not alter, transform or build upon this work. Registered charity no: 1090329.

NHS Confederation  
Portland House, Bressenden Place, London SW1E 5BH  
Tel 020 7799 6666  
Email [enquiries@nhsconfed.org](mailto:enquiries@nhsconfed.org)  
[www.nhsconfed.org](http://www.nhsconfed.org)

Follow the NHS Confederation  
on Twitter [@nhsconfed](https://twitter.com/nhsconfed)