

Making the Case for Personalised Care for Adults with Asthma

Overview

This paper describes personalised care in asthma. We define personalised care and distinguish this from personalised medicine. We argue that the broader approach of personalised care will not only benefit the individual, but also health services and populations, by improving use of medicines and thereby reducing waste, harm and potentially avoidable use of emergency care. We summarise this as improving value. The paper then makes recommendations about how policy-makers, clinical educators and patient leaders can contribute to the cultural and clinical changes that are needed to make personalised care for adults with asthma and other chronic respiratory diseases a reality.

What are personalised care and personalised medicine?

Personalised care

The concept of personalising care is not new. Understanding an individual's health needs and tailoring care to meet these has been a cornerstone of primary care for generations.¹ Personalised care, which is sometimes called person-centred care or personalisation, identifies what is most important to each person in their family and community context and ensures that the care they receive is designed around their individual needs. It supports patients to develop the knowledge, skills and confidence they need to manage and make informed decisions about their own health and health care more effectively.² This is important for patients with chronic conditions, such as asthma, who look after their own care almost all the time.³ Evidence shows that patients' ability to self-manage their asthma has a major impact on outcomes including asthma control, exacerbations, hospital admissions and quality of life.⁴

Personalised medicine

Up to now, much of the policy, research and media attention around personalised care has been focused on drug innovation, in particular, using genomic medicine to tailor prescriptions to individuals to improve their outcomes, and has been led by cancer research. It uses biomedical advances, including genome sequencing, to target therapies to achieve the best outcomes in the management of an individual patient's disease or predisposition to disease. It recognises that one disease may have many different forms, or 'subtypes', resulting from the complex interaction of biological make-up and diverse pathological and physiological processes. This marks a move away from the 'one size fits all' approach to the treatment and care of patients with a particular condition.^{2,5} It has recently been heralded in asthma using a 'treatable traits' approach.⁶ This is an important development because, after all,

chronic respiratory disease is responsible for more years of life lived with a disability than cancer.⁷

How can personalised care and personalised medicine support asthma care?

Recent research indicates that patients make decisions about whether to start and continue taking a medicine personalised to their own genetic profile in the same way as a non-personalised medicine, that is to say using their own beliefs and preferences.⁸ Therefore, understanding and taking account of patients' beliefs and preferences and helping them develop knowledge is essential to enable them to make informed treatment choices, including around personalised medicine. While personalised medicine offers enormous potential for improved outcomes for patients with asthma and other chronic respiratory

diseases, these potential benefits will only be realised if it is delivered within an overall framework of personalised care.

Why does personalised care matter in a time of constraints in health services?

Health policy is becoming more focused on the need to achieve value-based healthcare. Value has been defined as outcomes that matter to patients relative to the cost of delivering these.⁹ Therefore, value-based healthcare requires care that is personalised to individual patients' needs. Personalised care that takes account not only of a person's disease and their genome, but also their preferences, beliefs, other morbidities, and wider social and economic factors (such as their ability to pay for medications), improves clinical outcomes and satisfaction for individual patients. It also reduces waste of

Summary of Recommendations

Recommendation 1	Ensure undergraduate and continuing clinical education teaches the range of skills required to provide personalised care
Recommendation 2	Recognise the importance of shared decision-making in clinical guidelines and other tools to support diagnosis and treatment
Recommendation 3	Design inter-professional education and clinical pathways that encourage effective working across professions and organisations, including community pharmacists
Recommendation 4	Commission and ensure wide availability of different types of educational resources for patients
Recommendation 5	In guidelines and education explain that a personalised asthma action plan must be developed with the patient: 'nothing about me without me'
Recommendation 6	Ensure the guidance on using checklists and protocols explains how to use them appropriately
Recommendation 7	Update prescribing guidelines to insist inhaler brands should not be changed without discussion
Recommendation 8	Develop communication and audit tools to enable added value to be explained and measured
Recommendation 9	Advocate for the benefits of personalised care for clinicians and patients
Recommendation 10	Support research that answers questions about personalised care for adults with asthma

medicines and preventable hospital admissions which results in more efficient use of limited healthcare resources.¹⁰ Furthermore, personalised care can reduce population inequities by improving care for all patients and enabling a more equitable distribution of healthcare resources.

In summary, personalised care has the potential to improve value at different levels including:

Value level 1 - for patients: Improved clinical outcomes and satisfaction;

Value level 2 - for the healthcare system: Improved efficiency and sustainability with reductions in waste and avoidable emergency care and hospital admissions;

Value level 3 - for populations: More equitable distribution of resources.¹¹

How can we achieve personalised care for adults with asthma?

Recommendation 1: Ensure undergraduate and continuing clinical education teaches the range of skills required to provide personalised care

Novice and experienced primary care clinicians all need the personalised care skills to support patients to develop their knowledge and confidence to self-manage. At the heart of personalised care is compassionate communication. This involves elucidating the views and preferences of patients through open questioning and active listening and taking account of these when planning and reviewing treatment. It requires understanding and respecting the perspectives of individual patients. If clinicians are not adequately trained in the necessary skills to provide personalised care, they may feel anxious or lack confidence to engage meaningfully with patients by using open questions. It is therefore essential to ensure curricula include communication, shared decision-making and compassionate care skills as well as delivery, management and monitoring of asthma treatment pathways. When care is personalised, patients are more likely to accept the necessity of medication, have fewer concerns about adverse effects, understand their triggers and feel they have the ability to control their own asthma.^{12,13} *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2).*

An insight from a primary care nurse in the UK: "We need to understand and respect that 90% of the time patients with asthma and other chronic conditions are managing their conditions. They may not be managing them as we clinicians would like, but they are managing them."

Recommendation 2: Recognise the importance of shared decision-making in clinical guidelines and other tools to support diagnosis and treatment

How the diagnosis is made and communicated has a significant impact on

how patients feel about having asthma and their ability to self-manage. Enabling patients to share decision-making around diagnosis can help them accept the diagnosis.¹⁴ In addition, research has shown that shared decision-making, in which clinicians and patients negotiate a treatment regimen that accommodates patient goals and preferences as well as clinical evidence, improves adherence to asthma pharmacotherapy and clinical outcomes in adults with poorly controlled asthma.¹⁵ Shared decision making has four key defining features. Both clinician and patient:

1. Share relevant information;
2. Express treatment preferences;
3. Deliberate the options; and
4. Agree on the treatment to implement.¹⁶

Clinical guidelines and other tools used in managing asthma, such as asthma review checklists and templates, need to incorporate shared decision-making. *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2).*

Recommendation 3: Design inter-professional education and clinical pathways that encourage effective working across professions and organisations, including community pharmacists

Personalised care requires that different professionals share information and knowledge about a patient's preferences and decisions within and across organisations. Effective use of medicines by the patient requires consistent messages and repetition by all the professionals involved in their care pathway. Therefore, professionals need the same skills training and there are advantages in learning together, to share different perspectives. In particular, we argue that suitably trained community pharmacists have a key role in supporting patients to use their medicines effectively, including explaining dosages and reviewing inhaler technique, for which they require training in the necessary skills and appropriate compensation for the time needed to undertake this role. This can enable delegation of responsibilities and more effective division of tasks. *This improves efficient use of healthcare resources (value level 2).*

Recommendation 4: Commission and ensure wide availability of different types of educational resources for patients

There is no single educational resource that meets the needs of all patients. People learn differently. Some take in information more easily through visual aids or 3D models, while others prefer auditory approaches – including recordings of consultations. In addition, while many patients prefer to take away information in leaflet form, others are more comfortable being referred to trustworthy websites. Consequently, there is a need for different types and formats of resources to explain what asthma is and how it can be managed using language validated for the local context; it

cannot be assumed terms such as "wheeze" and "breathlessness" have the same meaning globally.¹⁷ Professional and patient societies, national health information programmes and suppliers of electronic health record systems need to review what is available and where necessary commission new resources. Healthcare providers should commit to using and referring patients to them. *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2).*

Recommendation 5: In guidelines and education explain that a personalised asthma action plan must be developed with the patient: 'nothing about me without me'

Despite being recommended since the 1980s, personalised asthma action plans (PAAP) are still underused. Research indicates there is a vicious cycle where professionals infrequently review and where necessary update PAAPs with patients; patients with out-dated PAAPs do not value or use these; professionals observing patients' lack of interest in PAAPs do not discuss these. Increasing the use and perceived value of PAAPs requires clinicians to develop asthma plans in discussion with patients.¹⁸ This needs to be reflected in guidance on PAAP and asthma reviews. *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2).*

A UK patient's perspective on their asthma review: "My annual asthma review takes 10 minutes. Every year I see a different nurse. The nurse works through a checklist of questions on the computer and gets me to demonstrate my inhaler technique. There's no discussion. They might as well send me the checklist to do by myself."

Recommendation 6: Ensure the guidance on using checklists and protocols explains how to use them appropriately

Checklists, protocols and incentives exist for a good reason: to ensure care is provided in line with accepted practice and evidence. However, over-reliance on checklists can be counter-productive.¹⁹ They are tools and cannot replace communication between clinician and patient. This needs to be reflected in guidance on how to use checklists and protocols, which might include the use of these checklists in advance, in the waiting room or at home, before the consultation. *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2).*

A view from a primary care physician in Ireland: "The drive to protocol driven healthcare reduces personalised care. Patients aren't servers of information for tick-boxes"

Recommendation 7: Update prescribing guidelines to insist inhaler brands should not be changed without discussion

In recent years, the importance and number of generic and branded generic medicines has increased as awareness about their economic benefits has spread. However, research shows patients and professionals place less trust in generic than branded medicines.²⁰ Information, education and trust in clinicians are key factors in improving trust in generics.²¹ It is also important to consider that different inhalers require different techniques. Consequently, there are safety implications of prescribing or using a different inhaler to fill a prescription, including a generic or branded generic instead of a branded device, as this creates the risk of over-dosing and under-dosing. Inhaler brands should not be changed without discussion with the patient for safety reasons; and the prescriber should then specify the agreed brand and device name for the pharmacist. Furthermore, training and incentives need to reflect that community pharmacists have a key role in helping patients manage changes in inhaler (see recommendation 4). *This improves patient outcomes (value level 1) and efficient use of healthcare resources (value level 2). Less waste will free up resources for allocation to other population health needs (value level 3).*

Recommendation 8: Develop communication and audit tools to enable added value to be explained and measured

It is important to describe the added value of appropriate treatments, adherence to treatment and treatment pathways, including the costs of inhalers and their benefits, to clinicians and patients. This can be done in simple ways, for example explaining the number of doses in different inhalers as well as relative costs. Added value also needs to be measured. This should include:

1. Better asthma control;
2. Improved patient experience, wellbeing and quality of life;
3. Economic benefits in terms of reduced long-term economic burden in healthcare and social care and lost or reduced productivity at work.

Tools that enable asthma control to be measured, such as ACQ (Asthma Control Questionnaire) and ACT™ (Asthma Control Test), need to be more widely used to measure the added value of appropriate treatments.²¹ *This improves efficient use of healthcare resources (value level 2) and a more equitable distribution of resources (value level 3).*

A perspective from a health economist: "We need to consider not only the delivery of appropriate treatment according to accepted guidelines but also the monitoring of the treatment success according to key performance indicators, including clinical outcomes, patient relevant outcomes, cost and economic benefits."

Recommendation 9: Advocate for the benefits of personalised care for clinicians and patients

Clinicians report being concerned that they have insufficient time to implement personalised care. However, it can result in less waste and more efficient use of healthcare resources, including primary care clinicians' time.²² Specifically, patients are more likely to be adherent, have better outcomes and need less emergency care. Policy-makers and professional organisations need to demonstrate and communicate the feasibility of personalised care in primary care. *This improves efficient use of healthcare resources (value level 2) and a more equitable distribution of resources (value level 3).*

Recommendation 10: Support research that answers questions about personalised care for adults with asthma

A recent review of interventions found individual studies demonstrated that shared decision-making for patients with asthma offered benefits on quality of life; patient and carer satisfaction; adherence to prescribed medication; reduction in asthma-related healthcare visits; and improved asthma control. However, limitations in individual studies compromised overall conclusions and the review concluded further research was needed.²³ This research needs to be set in the context of the investment in personalised asthma medicine, to ensure that the overall value of personalised care is calculated and understood. *This improves efficient use of healthcare resources (value level 2) and a more equitable distribution of resources (value level 3).*

How were these recommendations developed?

These recommendations were developed from the consensus reached by participants at an international meeting on personalised care for adults with asthma organised by the IPCRG. The meeting used a review of relevant research to formulate these consensus points. Participants came from six European countries

and have professional and/or personal experience of the diagnosis and treatment of asthma in primary care. They included people with asthma, family physicians, researchers in public health, behavioural psychologists and health economists, a community pharmacist and a primary care nurse practitioner.

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Personalised care: adults with asthma

IPCRG has produced a desktop helper intended to help clinicians working in primary care to provide personalised care to adult patients with asthma. It focuses on each of the following key stages of asthma management:

- **Diagnosis:** How diagnosis is made and communicated is very important as it has an impact on how patients feel about having asthma. This in turn will influence their ability to self-manage.
- **Treatment planning:** Treatment needs to be planned together with the patient and must take account of their priorities and preferences. This means the patient is more likely to adhere to treatment because they are confident it is necessary, is likely to be effective and takes account of their preferences as far as possible.
- **Treatment reviews:** Treatment reviews are important opportunities to follow up on how effectively patients are managing their symptoms. For reviews to be effective, patients need to be enabled to give their own perspective and describe how they are using medication.

The desktop helper provides practical guidance on questions to ask, advice to give and action to take at each of these stages. It has been developed with the input of patients, researchers and clinicians. A set of teaching slides to support clinicians is also available.

Listening and responding to patients' views and preferences



The complete 2-page desktop helper **Personalised care: adults with asthma** and teaching slides are available at www.ipcr.org/personalisation