

Personalised care for adults with asthma An experience-led care meeting on 6th October 2017 *Consensus Points*

Background

This document summarises the points of consensus reached by participants at a meeting on personalised care for adults with asthma. The participants were invited because they 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 psychology and health economics, community pharmacist and a primary care nurse practitioner. Participants came from six European countries.

The meeting was the first point in a project the IPCRG is leading for the creation, design and diffusion of a new package of educational resources on personalised care for adults with asthma. These will include an IPCRG desktop helper, a position paper and a set of teaching slides for primary care on personalised care and shared decision-making, using asthma as the exemplar. The consensus points from the meeting described in this document will be used to develop these resources. GSK have committed grant funding to IPCRG for this project.

The aims of the meeting were:

- To enable participants with different experiences of asthma care, including people with asthma, clinicians¹ and researchers, to exchange and reflect on their experiences of personalised care and shared decision-making for asthma care and the evidence that relates to this.
- To use this evidence and experience to develop the key points for a desktop helper (a 2 page document including practical guidance for clinicians) and an IPCRG position paper (an advocacy document, outlining what IPCRG stands for and believes should be happening).

The participants in the meeting were Stephanie Taylor (Chairperson), Juliëtte Kamphuis, Breda Flood, Jaime Correia de Sousa, Esther Metting, Darush Attar-Zadeh, Christoph Werner, Derek Forde, Phil Jefferies, Cristina Alonso Porcel, Ren Lawlor and Michela Tinelli. Siân Williams and Liza Cragg from the IPCRG also participated. Maggie Davis from GSK attended as an observer and did not participate.

Consensus points on definitions

- Personalised care is sometimes called person-centred care or personalisation.
- The following definition from the Health Foundation is useful “health and social care professionals liaise collaboratively with patients who access the services. Person-centred care supports patients to develop the knowledge, skills and confidence they

¹ The term “clinician“ is used here to mean a trained professional who works directly with patients so it includes pharmacists.

need to more effectively manage and make informed decisions about their own health and health/social care.”²

- Personalised care includes shared decision-making, personalised care planning and self-management support.
- The terms “personalised prescribing”, “precision medicine” and “personalised medicine” are commonly used by the pharmaceutical industry to describe individualised prescribing based on phenotypes.
- Personalised care involves the patient +their carer and takes account of their preferences . It has been an underpinning feature of family physician training for decades.
- Personalised care involves the patient/their carer and takes account of their preferences and has been taught in the family physician specialist curriculum for decades.
- The following definition of shared decision-making from the Kings Fund is useful “a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient’s informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients’ informed preferences.”³
- Personalised care and support planning puts people in control of their care and support. A personalised care planning approach is part of the delivery framework for a person centred approach to improving care for patients. Commissioners and providers should consider what an effective pathway looks like for a patient with long-term conditions and how personalised care and support planning can be built into that pathway. Once commissioners, patients, carers, and providers are clear on the agreed pathway, commissioners can begin to build this into their commissioning plans and work with the system to deliver it. Pathways may look very different for different patient groups, for example for someone newly diagnosed, individuals with multi-morbidities, proactive care, and crisis care.⁴

A primary care physician’s perspective: “Working with children has been a good experience for me. Children don’t do anything you tell them to do unless you can convince them that it is important. You must consider that they have different priorities from those of adults. Children are honest. You need to earn their trust. However, in primary care doctors often don’t have time and don’t take enough time to talk to patients. You have to let them talk and listen. In Germany one approach is to let the patient speak without interrupting them for at least the first seven seconds.”

Consensus points on key events for personalised care and shared decision-making, personalised care planning and self-management support in asthma

Diagnosis

- The first decision which is shared is around diagnosis.
- Start the consultation by asking the right question at the beginning – not “how are you?” but “why are you here today?”

² The Health Foundation. Person-centred care made simple. 2014.

³ Coulter A and Collins A. Making shared decision-making a reality. The Kings Fund, 2011

⁴ NHS England Personalised Care & Support Planning Handbook. Available at <https://www.england.nhs.uk/wp-content/uploads/2016/04/info-commissioners-care-support-planning.pdf>

- Diagnosis for most patients is not a clear decision made once because most patients do not have positive reversibility. Rather diagnosis is a process that may take place over several visits.
- When giving the diagnosis address the five components of the Common-Sense Model that help patients make sense of their symptoms and guide any coping actions.⁵ These are:
 1. *Identity*: the label or name given to the condition and the symptoms that 'appear' to go with it. This can be summarised as the question "what is it?"
 2. *Cause*: the individualistic ideas about the perceived cause of the condition, which may not be completely biomedically accurate. This can be summarised as the questions "what caused it?" and "why do I have it?"
 3. *Time-line*: the predictive belief about how long the condition might last, i.e. is it acute or is it going to be chronic? This can be summarised as the questions "how long will it last?" and "how long will the treatment last?"
 4. *Consequences*: the individual beliefs about the consequences of the condition and how this will impact on them physically and socially. This can be summarised as the question "what does it mean for me?"
 5. *Curability/controllability*: the beliefs about whether the condition can be cured or kept under control and the degree to which the individual plays a part in achieving this. This can be summarised as the questions "what treatment options are there?" and "can it be cured or controlled?"
- The high probability, intermediate probability or low probability of asthma BTS/SIGN guideline approach can be useful in discussing a diagnosis of asthma with patients. Decisions about treatment then depend on probability, ie high probability means they need to start treatment right away, intermediate probability means spirometry and further testing is recommended, low probability means keep looking for alternative diagnoses and refer for further tests.
- Ask the patient open questions about their own views on what might be wrong eg "what do you think it could be?"
- It is really important to understand the patient's existing knowledge and beliefs about asthma as part of the discussions around diagnosis.
- Explain what asthma is using props such as models, pictures, metaphors and videos.
- Discuss how patients feel about a diagnosis of asthma. Some patients may be very upset about their diagnosis, whereas others may be relieved.
- Explaining that asthma is manageable. It may be helpful to say many famous sports people and public figures have asthma.
- Help people to understand the potential benefits of an accurate diagnosis. One example (provided by Derek) is the likelihood of the reduced prescribing of antibiotics ("How many antibiotics did your child use last year? I can guarantee I can halve the numbers they use this year")
- Using a test of treatment (ICS not SABA) is one way to help patients participate in the decision of their own diagnosis. If the treatment stopped symptoms and symptoms returned after ceasing the treatment, this can help patients accept diagnosis.
- Because diagnosis may not be made at the first visit, symptoms may need to be coded or "suspected asthma" and reasons for this suspicion.

⁵ The Common-Sense Model is based on the work of Leventhal and colleagues. See the following for more: E. D. Hale, G. J. Treharne, G. D. Kitas; The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?, *Rheumatology*, Volume 46, Issue 6, 1 June 2007, Pages 904–906, <https://doi.org/10.1093/rheumatology/kem060>

- Write down the diagnosis and provide leaflets from patients' organisation and other reliable sources of information and links their internet sites.

Planning treatment with the patient and their carer

- Understanding the patient's goals is key to developing and agreeing a treatment plan.
- To understand the patient's goals ask questions like "where would you like to be in terms of your asthma in 6 months?" "what type of activities would you be able to do?" "how does it affect your daily life now and how would you like to change that?"
- Set tangible goals together. This should include short term goals (eg get through the night without waking) and medium term (eg have a cold without having an asthma flare up)
- Agree treatment together. Explain the recommended treatment for asthma would be an inhaler. As the patient questions about this such as "have you used an inhaler before? How did you find it?" and "how do you feel about using an inhaler?"
- Listen to the patient and let them know you care including direct eye contact and other signals of compassion and empathy (eg, "if you were my mum I'd prescribe you this...")
- Explain different the types of inhaler with patient. Explain which inhalers would be appropriate. Show the patient example inhalers. Discuss with the patient what might be important for them in an inhaler (eg how portable it is).
- Explain inhaler technique and demonstrate it using props. Set the seed that this will be followed up on at future consultations as most people tend to forget how to use them properly.
- Explain what spacers are for and discuss if they want or need one. The purpose of spacers and how to use them needs to be properly explained.
- Suitably trained community pharmacists have a key role in explaining inhaler technique as long as they are properly trained.
- When agreeing and prescribing treatment, it is important to bear in mind that different inhalers require different techniques. Inhaler brands should not be changed without discussion with the patient for safety reasons. If a patient gets a different inhaler (eg because of a change in procurement by the pharmacy) they may not use the correct technique which could result in an over or under dose.
- For this reason inhalers should be excluded from generic medicines requirements. In some countries this may not be feasible because the physician does not have the right to prescribe a branded inhaler over a generic version.
- Community pharmacists have a key role in helping patients manage unavoidable changes in inhaler.
- In some contexts the cost of inhalers can be an issue. Clinicians need to be aware of this and that it can lead to some patients rationing the use of their inhaler.
- Self-management is an integral part of treatment. Discuss self management together with the patient.
- Give examples of potential triggers, eg allergens, exercise, environmental factors.
- Identify potential triggers for the individual together with the patient and discuss how to manage these together.
- Be aware of the patient/carer's perspective and develop realistic strategies.
- Develop with the patient a written asthma action plan which explains clearly how to recognise something is going wrong, what to do and when and how to seek help.
- At the end ask the patient to summarise what you have agreed and check that they understand and support this.

When explaining inhaler technique, prime the patient that this will be reviewed as a matter of course by saying "we all drift off in our techniques over time, so we will check in with you from time to time." Explain that this may be repeated at the pharmacy.

Community pharmacists need to introduce their explanation of inhaler technique by saying “lots of people don’t use these correctly, so it’s best to show you how to use it. It will take about 10 mins to show you and for you to have a go. Is that OK?”

An example of adapting treatment to adapt to the patient’s perspective: “Telling a patient whose asthma is triggered by a cat allergy to avoid cats when their grandmother who they visit often has a cat, is not going to be feasible. So instead suggest taking an increased dose before visiting.

A primary care clinician’s perspective: “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 as clinicians would like, but they are managing them.”

Treatment reviews with the patient

- Discuss the possible frequency of a review and what the purpose of the review is together with the patient.
- Offer choice of format of the review. Telephone, email, and app reviews can be effective.
- Agree the frequency.
- Ask the patient to complete a questionnaire to assess their symptoms, eg CARAT⁶, ACT⁷.
- Ask the patient open questions to encourage them to talk about their asthma management eg “how do you feel about your asthma at the moment?”
- Fear can drive behaviour and communication so before asking if a patient has followed the treatment plan, set the scene to enable them to be able to report if they have changed it, eg “it is common for patients to change the treatment plan”. Then ask the patient about this, eg “did you have to adapt your treatment plan? And were you able to reach your goals?”
- Give constructive feedback to the patient from the role as a coach who is helping them to reach their goals, rather than judging them.
- Ask them to reflect on how they are doing themselves.
- Describe the added value of appropriate treatments, adherence to treatment and treatment pathways, including the costs of inhalers and their benefits, eg this inhaler costs x and contains y puffs. Many patients have no idea about this. Added value should include the following: 1. better asthma control; 2.improved patient experience, wellbeing and quality of life (see patient relevant outcome measures); 3. economic benefits in terms of reduced long-term economic burden in health (see use of health resources such as hospitalisation, visits, exams, etc) and social care (see use of social services/ access to care homes) and reduced loss productivity at work.
- Do not judge or blame patients for using alternative therapies. Clinicians need to give patients’ the opportunity to explain what therapies they are using as this is important information. People often like going to alternative therapists because the therapist listens to their whole story.
- If the patient is doing well discuss opportunities to step down treatment (including explaining at the outset that we want to use the lowest dose possible)
- Ask the patient in advance to bring their own inhaler and check inhaler technique and repeat advice. Explain that you are doing thing because most people tend to forget how to use them properly, not to check up on them.

⁶ Available at: <http://www.caratnetwork.org/>

⁷Available at: <http://www.asthmacontroltest.com>

- Monitor treatment performance, including clinical outcomes, patient relevant outcomes and economic benefits. The primary care team have a pivotal role in collecting relevant information using appropriate/ readily available tools.
- Asthma review checklists may be helpful but should be used as a way of prompting points of conversation and recording shared decisions, rather than as a standard “tick box” exercise. It is the quality of the conversation and interaction that counts, rather than the tool itself, eg “Is your asthma bothering you at the moment?”
- Where asthma review checklists are used as “tick box” exercises they can actually close off meaningful conversations about how patients are doing, for example if the professional completing them focuses on the computer, rather the patient (provided by Phil).
- How able patients are to take responsibility and action themselves, known as patient activation levels, to manage their asthma, change over time so don’t assume a patient who doesn’t seem to want to engage immediately after diagnosis won’t do so later. Likewise, a patient who has been self-managing well for a long period may stop doing for some reason (eg a bereavement).
- There are apps available that some patients may find useful to manage their asthma (eg for recording peak flow, medication use and symptoms)
- Follow up on repeat prescriptions to see if the patient is requesting these at intervals that match the prescribed use of the medication. In contexts where the clinician has access to pharmacy records, follow up prescriptions to see if the patient has picked these up.
- At the end ask the patient to summarise what you have agreed and check that they understand and agree.

A patient’s perspective on their 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.”

Consensus points on key themes

Healthcare professional-patient/carer communication and education

- The quality of the conversation between the patient/carer and the clinician is key at every stage of shared decision-making. During the conversation there should be room left for the patient to ask questions and express their feelings, without being rushed. The patient needs to feel they have been heard and to get value out of the conversation.
- “Lack of time” may be given as a reason for not doing or trying things, but there may be more efficient ways to use the given time.
- Clinicians are sometimes afraid of allowing the patient to talk because they worry the patient might take too much time. However, patients will rarely talk for longer than 30 seconds without stopping. Allowing them to talk uninterrupted at the beginning of the consultation will enable them to tell you how they are and what their concerns are.
- If clinicians lack experience or confidence, they may be worried that a patient will ask a question they cannot answer. If this is the case, the patient may pick up on this and feel the consultation is being rushed.
- Asking open questions is very important (eg “how do you feel about your asthma?” or “is there anything you’d like to tell me about your asthma?”).
- Ask patients what they know about asthma before explaining. This can actually save time as the patient might already know quite a lot.
- Patients may be unlikely to disagree or challenge the clinician because they worry about seeming rude or disloyal or the potential impact for future care. It is important to give patients the opportunity to voice their own views, experiences, preferences and feelings about the proposed diagnosis and treatment.

- There is no one single approach to sharing information with patients. All patients learn differently, eg some people take in information more easily through visual aids and others through auditory approaches. This means different kinds of tools are needed to explain what asthma is including metaphors, films, models and pictures.
- The same is true of clinicians: they take in information and learn in different ways.
- Sometimes there may be a mismatch between the clinician's way of absorbing information and the patient's: so try different approaches.
- Warning about the negative consequences of doing something is not in itself effective: fear is not motivating. Telling patients of risks can make them disengage.

Checklists, protocols, monitoring and incentives

- Checklists, protocols and incentives exist for a good reason: to ensure care is provided in line with accepted practice and evidence. However, if they are reduced to tick box exercises they can be counter-productive because this prevents communication.
- Checklists, protocols and incentives are tools. They can't replace communication between clinician and patient but they keep the conversation on track – to elicit the right data to help decision-making.

A primary care physician's perspective: "the drive to protocol driven healthcare reduces personalised care. Patients aren't servers of information for tick-boxes"

A health economics perspective "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 and economic benefits."

Compassionate care

- Patients deserve to be treated with compassion and dignity.
- When clinicians use phrases that indicate they personally empathise with and care for the patient, this can help develop trust.

An example one way of underlining that the patient is cared for "I'm going to ask you again about this (eg smoking) because we care for you."

Consensus points on the implications for policy

- Personalised care and shared decision-making are regarded as the gold standard approaches in many aspects of healthcare delivery because they have the power to reduce variation and improve medicines use but, despite the prevalence of asthma and the unwarranted variation in asthma care, it has received little policy attention
- At the heart of personalised care is compassionate communication.
- Clinicians need to be properly trained in communication/education skills, compassionate care skills, clinical knowledge of asthma, but also delivery, management and monitoring of asthma treatment pathways. If they are not, they may feel very anxious and not be confident enough to meaningfully engage with patients by using open questions. An example (given by Ren) was that registered nurses training in the specialism of primary care may be expected to be responsible for doing asthma reviews with just one day respiratory training on top of their basic nurse training.
- Community pharmacists may be an under-used professional resource, but they require training and the right incentives to support people with asthma effectively.
- The health system needs to incentivise collaboration between the nurse, GP and pharmacist rather than encourage turf wars. Effective use of medicines by the patient requires repetition and reinforcement which requires the same technique training and

shared knowledge about medicines use. This can enable delegation of responsibilities/task shifting and sharing.

- Inter-professional education can help achieve this.
- It is difficult to give consistent care in systems with part-private care, where there is no incentive to share records and information with all colleagues. In these circumstances the use of patient-held records may be beneficial eg Patient Knows Best online records
- There are many different types of inhaler. Requirements to provide generics and pharmacy supplier preferences may mean patients get a different inhaler which needs different technique without this being adequately explained.
- There are safety implications of prescribing or using a different inhaler to fill a prescription (eg a generic instead of a branded device). Pharmacists sometimes don't explain this to patients. This creates the risk of over-dosing and under-dosing.
- There are different models of care and regulations for prescribing in different countries. This means it is not possible to come up with "one size fits all solutions".
- Group sessions may save time to be used on other aspects of the consultation eg for inhaler technique training or explaining about PAAPs