



# Ankylosing Spondylitis Personalised Care Plan

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## Presenter Disclosure Information:

Conflicts of interest

The speakers have no conflicts of interest

# Session aims

- Introduce the concept of Personalised Care Plans (PCP)
- Discuss the development process undertaken for the AS PCP
- Present the AS PCP

# Ankylosing Spondylitis: a long term condition

- 15 million people in England =  $\geq 1$  long term condition
  - Use 52% of GP appointments  
population
  - Use 65% of outpatient appointments
  - Poorer Quality of Life
- account for 31%  
of the

Focus on medical needs & treatments

Limited attention on social, psychological & holistic needs

# Ankylosing Spondylitis: a long term condition

- 90% of individuals with long term conditions feel comfortable taking responsibility for their own health (1) Ipsos/Mori April 2009
- > 75% LTC patients would feel more confident with self-caring if they had help from a health professional

Limited knowledge of their condition

Limited influence over their care

No plan for managing their condition

# The modern NHS – operating framework

## *Commissioning for Health and Wellbeing:*

- More individualised services
- More focus on prevention of disease and complications
- Greater choice – including supporting people to make healthier and more informed choices
- Reducing health inequalities

The demands of  
the modern NHS

Empowering patients  
with LTC's



**Do you or your child have  
a long term condition?**



**Did you know a care plan  
will help you manage your  
condition better?**



**Your health,  
your way,  
your choice.**

The NHS poster features a white background with a blue NHS logo in the top right corner. It contains two main sections of text in bold purple font, each followed by a cartoon illustration. The first section asks if the viewer or their child has a long-term condition, accompanied by an illustration of a young child in a wheelchair, a woman, an elderly woman in a wheelchair, and a man. The second section asks if the viewer knows a care plan can help manage their condition better, accompanied by an illustration of three healthcare professionals: a man, a woman, and a man. At the bottom right of the poster, there is a blue box with the slogan 'Your health, your way, your choice.' in white text.

# Commitment to Personalised Care Plans

## **Our Health, Our Care, Our say: (3)**

- Commitment to all patients with a LTC being offered a PCP by 2010 should they want one

## **The Operating Framework for the NHS in England 2009/10: (4)**

- “Over the next two years, to ensure that those living with a long term conditions receive a high quality service and help to manage their condition, everyone with a long term condition should be offered a personalised care plan.”

## **The High Quality Care for All: NHS Next Stage Review Final Report: (2)**

- *“Over the next two years, every one of the 15 million people with one or more long term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care.”*





# What is Personal Care Planning?



Recognising the impact of non-medical issues

Addressing an individual's full range of needs

# Stages in Personalised Care Planning

Stage 1: Newly diagnosed & reassessment

Stage 2: Living with a long Term Condition

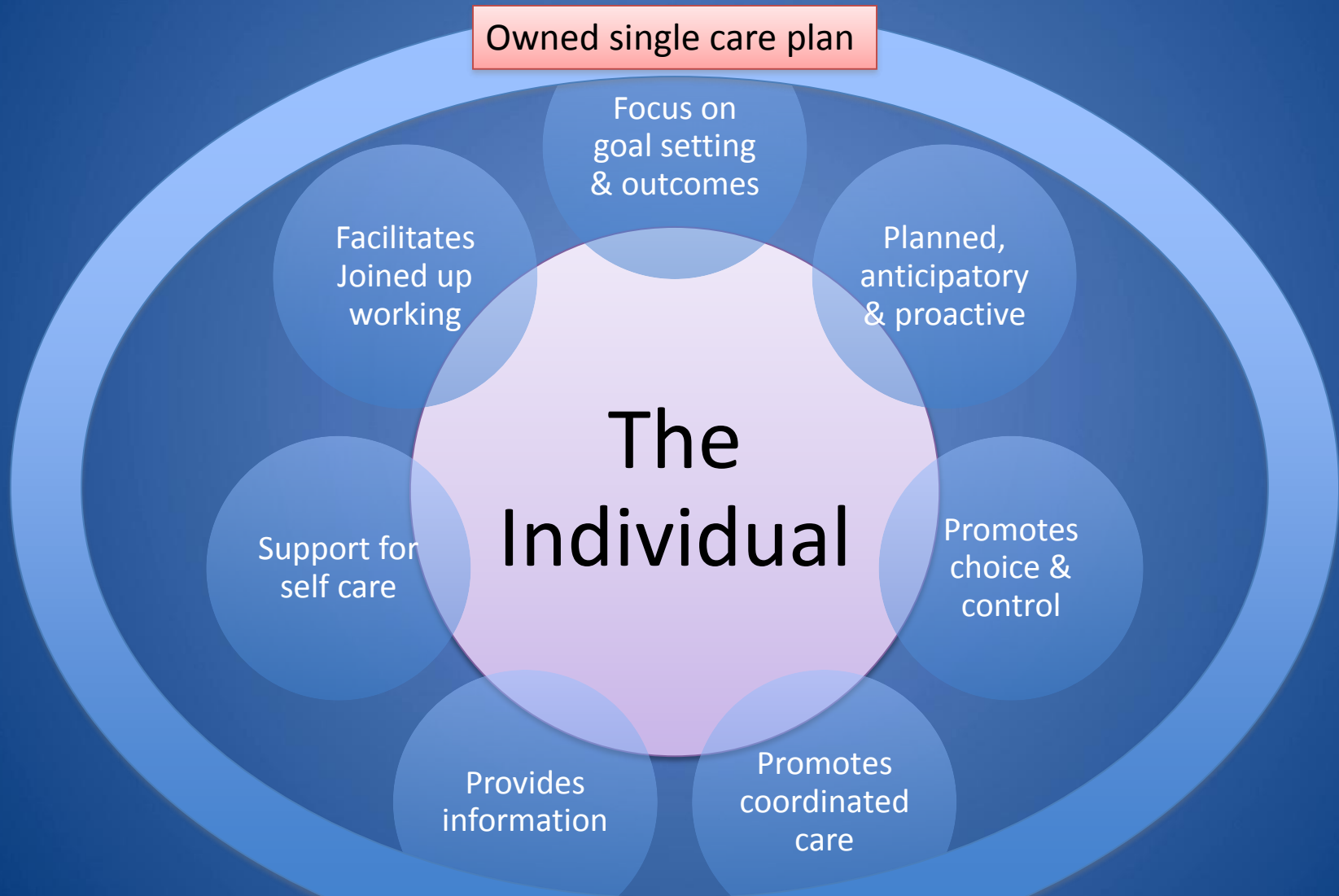


A journey of changing individual needs



shared decision - being given choices & genuine options, becoming empowered

# The Care Planning Process – key elements



# Expected Benefits – patient <sup>(5)</sup>

Sustained health,  
independence &  
social inclusion

Greater ability to  
work

Broader range of  
tailored choices

Empowered,  
confident to self  
manage

Better  
management of  
medicines & risk

Reduced crisis  
episodes

Better long term outcomes

# Expected Benefits – service <sup>(5)</sup>

Standardised good  
quality of care –  
improved  
outcomes

Better  
management of  
risk

Reduced GP  
appointments <sup>(7  
& 8)</sup>

Reduced  
unplanned  
admissions

Joined up,  
coordinated  
service

Less duplication of  
information service  
to patient, patient  
to service

Reduction in  
complaints

Clinical & cost  
effective

Proactive rather than reactive

# Individual Personalised Care Plan

- A written (or electronic) record
- Owned (and looked after) by the individual
- For individuals to share with family / carers
- For individuals to share with other health care professionals
- Dynamic / reviewed
- Holistic – seeing the person ‘as a whole’

# My Personal Care Plan

## Living with Ankylosing Spondylitis

Working in partnership with

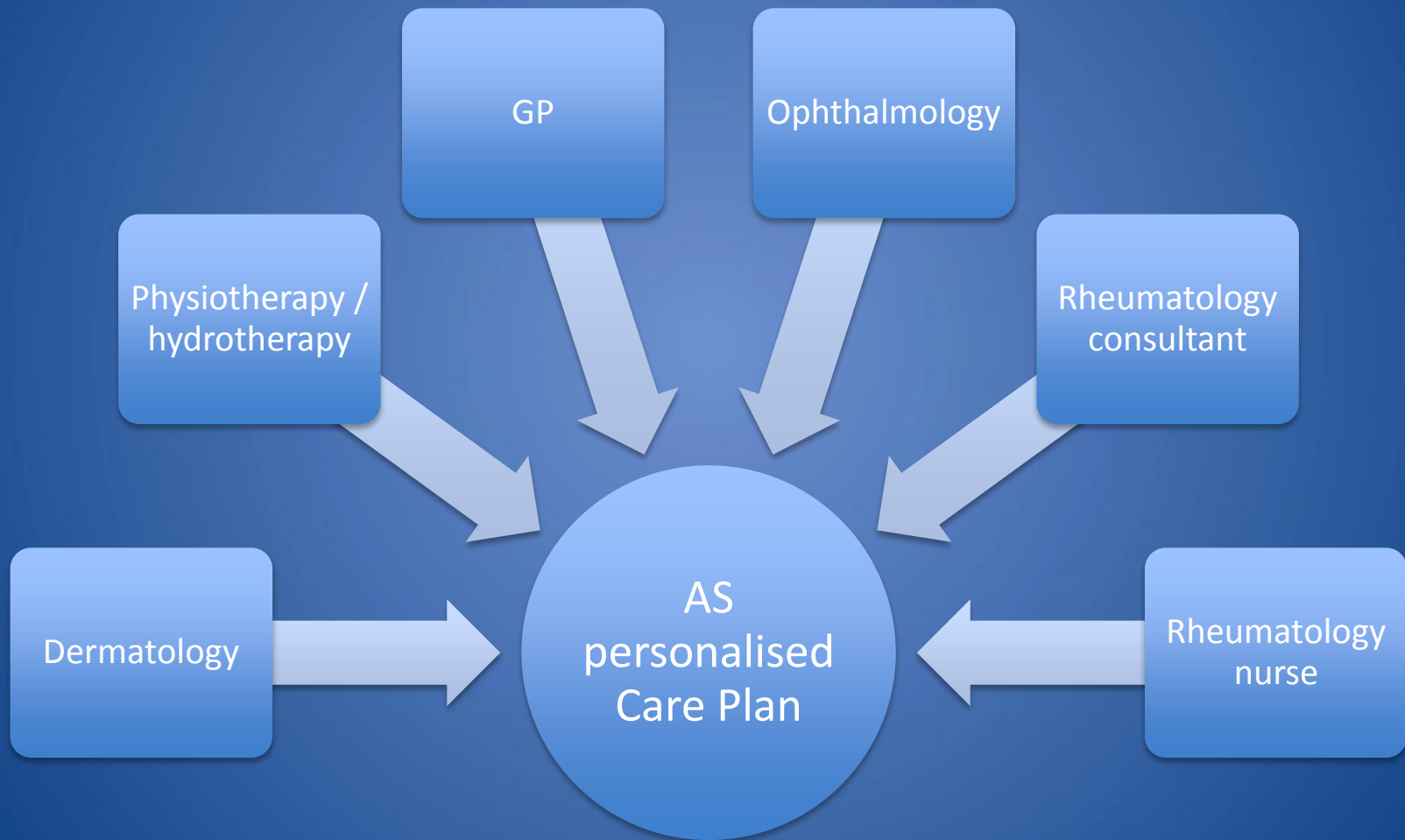
Solent NHS Trust

&

Portsmouth National Ankylosing Spondylitis Society Group



# AS Personalised Care Plan





# Development of the AS Care Plan

CNS and Physio planning:

Literature, supporting information, format & design

1<sup>st</sup> draft

Focus group – local AS patients

2<sup>nd</sup> draft

Peer review: local MDT, Astretch committee, RCN rheumatology forum

Focus group - local AS & NASS group members

3<sup>rd</sup> draft

NASS head office review

AS care plan launch – Portsmouth November 2012

# What is in the AS Individualised Personal Care Plan?

Key facts & self  
management  
concepts specifically  
for AS

Guidance &  
management  
concepts for  
secondary conditions

Exercise principles for  
AS and secondary  
conditions

Self monitoring  
including goal setting

Consultation planning  
/ review

Signposting - national  
and local resources

# What is in the AS Individualised Personal Care Plan?

## KEY FACTS:

- The condition
- Associated health conditions / risks
- Exercise management
- Posture management
- Pacing activity
- Pain.....

# What is Ankylosing Spondylitis

- An inflammatory condition (that is different to Rheumatoid Arthritis or Osteoarthritis)
- The condition can be seen to have 2 main phases:
  1. Episodes of inflammation where soft tissue (ie: your tendons and ligaments) insert into bone – this occurs mainly at the spine
  2. Extra formation of bone produced at the site where the inflammation occurred
- During a phase of inflammation you may feel pain and fatigue – this can also be referred to as a “flare of your condition”
- Repeated extra bone formation may lead to stiffness in the spine over time as the normal elastic soft tissue is replaced by bone. In some cases the new boney formations can bridge across vertebral bodies (the bones in your spine) causing fusion of the spine.
- People with Ankylosing Spondylitis can experience repeated episodes of inflammation at different sites in the spine (or else where in the body where soft tissue inserts into the bone ie: the heel, breast bone) but it is not yet possible to truly predicated how often or how intense the episodes may be from person to person
- Similarly it is not possible to say if, or to what degree, a person may become stiff in their spine due to extra bone growth

**Ankylosing Spondylitis is different to “mechanical low back pain” and different to general wear/tear of the spine that is seen in osteoarthritis**

**If you are diagnosed with Ankylosing Spondylitis it does not mean that you will become disabled or wheelchair bound**

**Remember – not all people with Ankylosing Spondylitis have the same level of symptoms – you are all different and individual**

**Over a course of days, weeks or months it is common for you to have varying levels of pain, fatigue and stiffness**



## Know your Cardiovascular risk

Research has shown that patients with Ankylosing Spondylitis have an increased risk of developing cardiovascular disease and having incidents such as heart attacks or strokes.

Attending annual cardiovascular risk assessment (with your GP or at your annual Rheumatology review) is important.

As you already have increased risk, reducing all of your cardiovascular risks is essential. The following self management actions need to be considered:

1. Maintaining a healthy blood pressure level
2. Eating a healthy diet
3. Maintaining a healthy weight

4. Exercising regularly to improve your cardiovascular fitness
5. Stopping smoking (if applicable)
6. Controlling / reducing stress levels

Blood Pressure	Cholesterol levels	Smoking	Cardiovascular Exercise
<p>This result tells how hard the heart has to work to move the blood around your body</p> <p><b>Healthy Range</b> 140/80 or less</p> <p>The following actions can help you to maintain a healthy blood pressure:</p> <ul style="list-style-type: none"> <li>•Regular cardiovascular exercise</li> <li>•Healthy Eating – less salt, less saturated fat, 4-5 portions of fruit and vegetables a day</li> <li>•Limiting alcohol intake: 3-4 units for men and 2-3 units for women per day</li> <li>•Stop smoking</li> </ul>	<p>Raised levels of some lipids (“bad fats”) in the blood are seen in people with Ankylosing Spondylitis.</p> <p>Key actions that you can take to reduce your cholesterol levels include:</p> <ul style="list-style-type: none"> <li>•Eating a healthy diet</li> <li>•Remaining physically fit</li> <li>•Reducing your weight (if you are over weight)</li> <li>•Stopping smoking</li> <li>•Reducing your alcohol intake</li> </ul> <p>Assessment of your cholesterol levels should be undertaken by your GP. If you levels are outside of the normal ranges in some cases medications may be prescribed and should be taken in conjunction with the self management actions stated above. Regular review of your cholesterol levels with you GP should be organised.</p>	<p>Smoking increases cardiovascular risk. Smoking when you have Ankylosing Spondylitis can result in worse disease activity, poor functional ability, worse pain and poor quality of life.</p> <p>When giving up smoking people have more success when they use supplementary interventions ie: chewing gum, inhalers, patches or prescribed medicines. This success is enhanced further by accessing a support programme at the same time.</p> <p><u>To help you stop smoking:</u></p> <ul style="list-style-type: none"> <li>•Contact your GP to ask about products to reduce nicotine cravings</li> <li>•Contact sources of support: <b>NHS smoking helpline</b> 08001690169 <b>www.NHS.UK/GOSMOKEFREE</b></li> </ul>	<p>Current recommendations state that adults should be completing the following level of exercise to maintain a good healthy cardiovascular system ie: efficient working heart and lungs</p> <div style="border: 1px solid blue; padding: 5px; text-align: center; margin: 10px 0;"> <p style="color: red;">moderately intense exercise</p> <p style="color: red;">30 minutes, 5 times a week</p> </div> <p>Moderately intense exercise means working at a level that makes your heart rate increase slightly or makes you slightly short of breath.</p> <p>Considering your do not want to make any pain from you Ankylosing Spondylitis any worse, some exercises you might consider are: swimming, fast or power walking, cycling, stair climbing</p> <p><b><u>IF YOU FEEL UNWELL WHISLT EXERCISING - STOP AND SEEK MEDICAL ADVICE</u></b></p>

# Exercise

**If I had to choose one exercise ?**

## **SWIMMING**

It gives you a good cardiovascular work out, moves your joints and strengthens you all in one exercise. It works you hard without the weight bearing that may irritate your condition when performed to the same level on land

## **BUT**

Good technique is essential to ensure you do not swim with your neck in an extended position

**One piece of recommended exercise equipment ?**

## **GYM BALL / FIT BALL**

Relatively cheap  
Idea for use at home  
Can be accessed daily  
Can help to move your joints, strengthen, work your postural control / core and stretch you.

Ensure you are measured for the right sized gym ball before you buy it

Always look for “anti-burst” logos before you buy a ball

**Can I do “normal” gym and community classes ?**

## **YES!**

Classes / exercises to consider:

Yoga  
Pilates  
Tai chi  
Spinning  
Water aerobics  
Nordic walking  
Body balance  
Body pump.....

The only sports to avoid are contact sports ie: rugby, kick boxing etc. Some caution should be taken with rackets sports as they involve bending and twisting at speed

# What is in the AS Individualised Personal Care Plan?

## MONITORING:

- Bath scores
- Blood test results
- Weight
- BP
- Medication
- Exercise regime

# Monitoring your Ankylosing Spondylitis

Date & time	BASMI	BASDAI	BASFI	BASG	ASQOL	Work Instability

**BASMI** – a measure of spinal and hip movement. Scored out of 10. The closer to 10 the more restricted you are due to your condition.

**BASDAI** - a measure of disease activity. Scored out of 10. The closer to 10 the more active your condition is.

**BASFI** – a measure of functional ability. Scored out of 10. The closer to 10 the more functionally restricted you are due to your condition.

**BASG** – a measure of overall coping ability. Scored out of 10. The closer to 10 the greater impact your condition is having on your ability to cope.

**ASQOL** – a measure of quality of life. Scored out of 18. The closer to 18 the less quality of life you have due to your condition

**Work Instability** – a measure to assess your ability to remain at work and be productive at work. Scored out of 20. Scores above 12 may require further investigation or access to support to enable you to remain working





# Monitoring your Ankylosing Spondylitis

<b>Ankylosing Spondylitis Drug:</b>		<b>Start date:</b>
Review date	Dose taken	Overall effectiveness of drug (score 0 – 10) 0 = not effective / 10 = extremely effective
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# Monitoring your Ankylosing Spondylitis

<b>Week beginning</b>	<b>Exercise forms completed</b> (walking, yoga class, spinning class, swimming, stretching at home)	<b>Length of time exercise performed</b>	<b>Enjoyment rating</b> (score 0 – 10) 0 = not enjoyable 10 = extremely enjoyable

# What is in the AS Individualised Personal Care Plan?

## GOAL SETTING:

- Individual to you
- Realistic
- Actions agreed
- Time scales / reviews set

# My personal goals

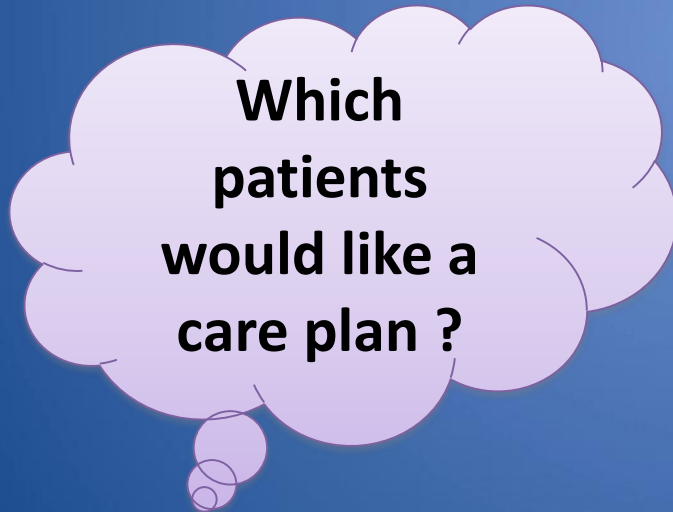
Date	Goal I would like to achieve	What actions am I going to take to achieve it	By when	Achieved date

# Local implementation – November 2012

- AS annual review clinics
- AS anti-TNF clinics



Ongoing review of care plans



# Ankylosing Spondylitis

## Individual Personalised Care Plan

Male

Female

I would be interested in having a Individual Personalised Care Plan Yes  No

**I would prefer to collect care plan and complete my first Care Planning Discussion:**

(please feel free to tick multiple preferences)

- At my next AS clinic appointment
- Via a health professional speed dating event:  in the evening  during the day
- Via email
- Over the telephone
- A part of the NASS evening group
- Other (please state)

Thank you.

# The essence of Personalised Care Planning

## Working in partnership

Health professional  Patient

## Being informed & taking ownership

# Personal reflections

1. Formal way of showing what the majority of Health Professionals in Rheumatology already do
2. Platform for engaging all disciplines in the overall care of a patient
3. Good medium for standardising elements of care even at a local level
4. Really defining the patients goals
5. “yes please / “no thank you”!





**Individuals living with long term conditions spend approximately 3 hours every year with healthcare professionals...**

**for the other 8,757 hours they look after themselves**



# Thanks

- Local NASS group
  - Chairman
  - Members
- Local Healthcare professionals
  - Dr Young-min
  - CNS Ronnee Bunge-Tuble
- Peer reviewers
  - NASS HQ
  - AStretch
  - RCN rheumatology forum

# References

1. Ipsos/Mori April 2009
2. High Quality Care For All NHS Next Stage Review Final Report D/H June 2008
3. Department of Health. *Our health, our care, our say: A new direction for community services*. London. 2006.
4. Department of Health. *The Operating Framework for the NHS in England 2009/10*. London. 2008
5. Supporting People with Long Term Conditions: Commissioning Personalised Care Planning DH/Long Term Conditions 19 Jan 2009
6. Generic choice model for long term conditions DH Choice Policy Team Dec 2007
7. Department of Health. *Research evidence on the effectiveness of self care support* report. London. 2007.
8. The Commonwealth Fund. International Health Policy Survey of Primary Care Physicians in Seven Countries. 2006.
9. Department of Health. *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*. London 2007. (world class commissioning)
10. Your Health, your way – on NHS choices website - NHS guide to LTC & self care (for patients)
11. Improving care for people with long term conditions – information sheet 1 personalised Care planning DH 2010
12. Improving care for people with long term conditions – information sheet 5 what motivates people to self care DH 2010
13. Improving care for people with long term conditions – information sheet 6 Goal setting and action planning as part of PCP DH 2010