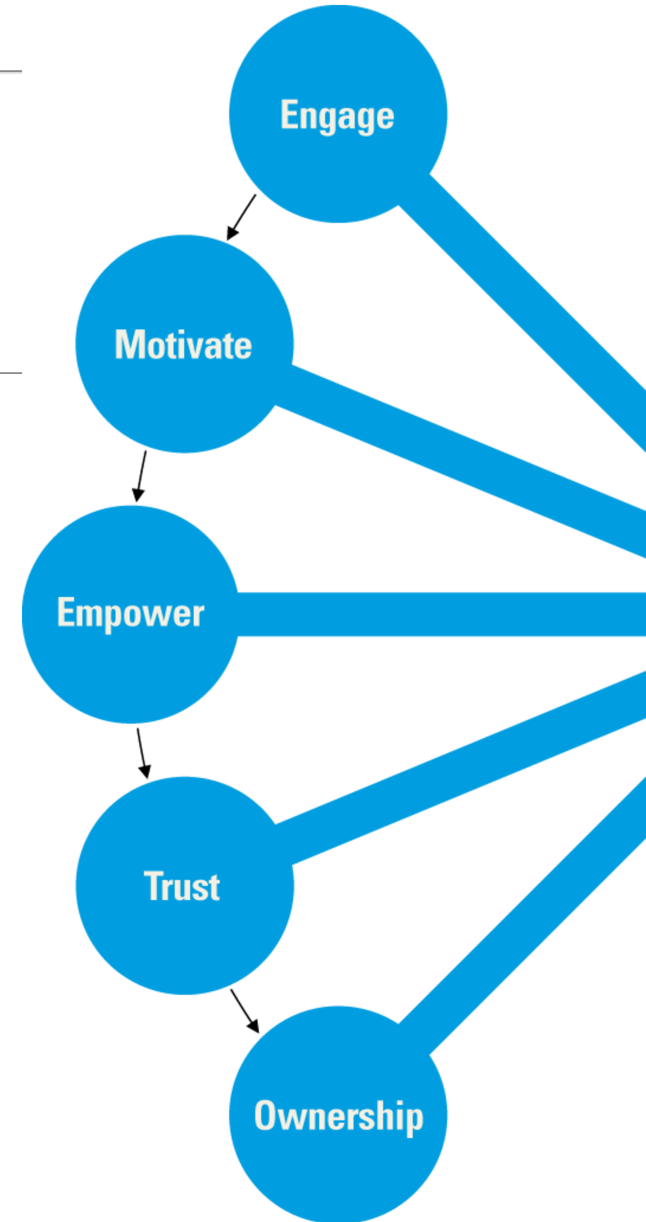
CSRCCG / GPCCG
5 YEAR PLAN ENGAGEMENT PATIENT INSIGHTS

"The NHS have done a fantastic job of adding years to life. I hope this 5-year plan will help add life to years."

"Long live the NHS!"



Collaborative Change ®

NEMS

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1.

INTRODUCTION AND BACKGROUND

They [the CCG] deserve credit for running these meetings. For once, I feel like I've actually been listened to—Diabetes

AIMS & OBJECTIVES

Aim

- Generate actionable citizen-patient insights to inform the development of a five-year strategic plan for Chorley & South Ribble (CSR) and Greater Preston (GP) CCGs.

Objectives

- Isolate 'patient satisfaction' as the primary metric for this study.
- Analyse the concept of patient satisfaction into its constituent parts.
- Understand the relative importance and interaction of these constituents in the context of specific:

    1. Service strands
    2. Long-term conditions
    3. Protected characteristics

- Model how future changes will impact on satisfaction.
- Develop recommendations for how patient satisfaction can be improved / preserved in the face of future changes.

OUR RESEARCH 'LENSES'

QUANTITATIVE

- 2000 telephone interviews
- Representative sample of the populations of CSR and GP
- Dedicated F2F sub-sample of 200 BME respondents to detect significant differences
- Focussed on 4 distinct service strands:
  - **Hospital (planned)**
  - **Hospital (emergency)**
  - **Community Care**
  - **GP**
- Booster sample of 320 drawn from CSU activity:
  - **GP Surgeries: 250**
  - **Online survey: 70**

GENERAL POPULATION

OUR RESEARCH 'LENSES'

QUALITATIVE

- 22 focus groups / engagements / listening events
- A total of 318 participants
- Sample recruited through services, community groups and patient panels
- Focussed on a range of long-term conditions:
  - **Diabetes**
  - **COPD**
  - **Mental Health (MH)**
  - **Dementia**
  - **ME / CFS**

SPECIFIC POPULATIONS

OUR RESEARCH 'LENSES'

QUALITATIVE

- 22 focus groups / engagements / listening events
- A total of 318 participants
- Sample recruited through services, community groups and patient panels
- Focussed on a range of long-term conditions

- Protected Characteristics:
  - **Learning difficulties (LD)**
  - **LGBT**
  - **BME**
  - **Visual impairment (VI)**
  - **Physical disabilities (PD)**
  - **Maternity & Pregnancy**
  - **Carers**

SPECIFIC POPULATIONS

OUR RESEARCH 'LENSES'

QUALITATIVE

- 22 focus groups / engagements / listening events
- A total of 318 participants
- Sample recruited through services, community groups and patient panels
- Focussed on a range of long-term conditions
- Protected Characteristics.
- And topics of interest:
    - **Transport**

SPECIFIC POPULATIONS

OUR RESEARCH 'LENSES'

22 ENGAGEMENTS

318 PARTICIPANTS

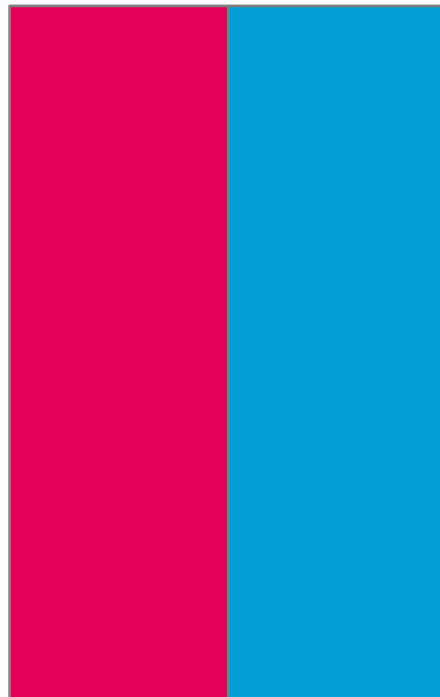
2.

UNDERSTANDING PATIENT SATISFACTION

The NHS shouldn't try to save money – it should be free to all—PD

PATIENT SATISFACTION

SATISFACTION IS A COMPLEX CONSTRUCT



Patient satisfaction is a complex construct, determined by interplay between service quality and patient expectation.

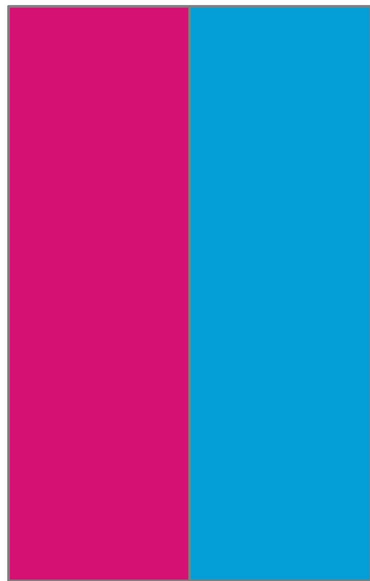
A wide range of factors will determine patient expectations, including:

- Urgency of condition
- Severity of condition
- Subjective state of mind
- Previous experience of service
- Media coverage
- Social/cultural norms

PATIENT SATISFACTION

SATISFACTION IS A COMPLEX CONSTRUCT

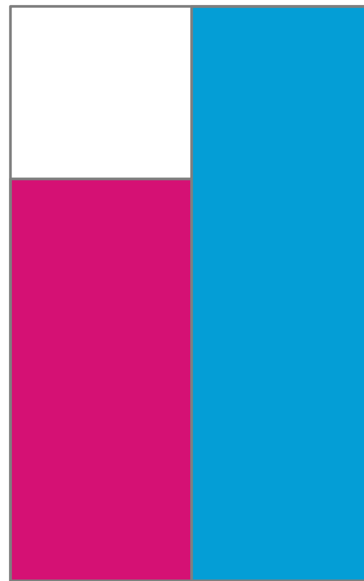
Optimum Satisfaction



Service Quality   Patient Expectation

When service quality meets expectation we achieve optimum satisfaction.

Dissatisfaction



Service Quality   Patient Expectation

When service quality falls short of expectation we create dissatisfaction.

Surplus Satisfaction

Service Quality   Patient Expectation

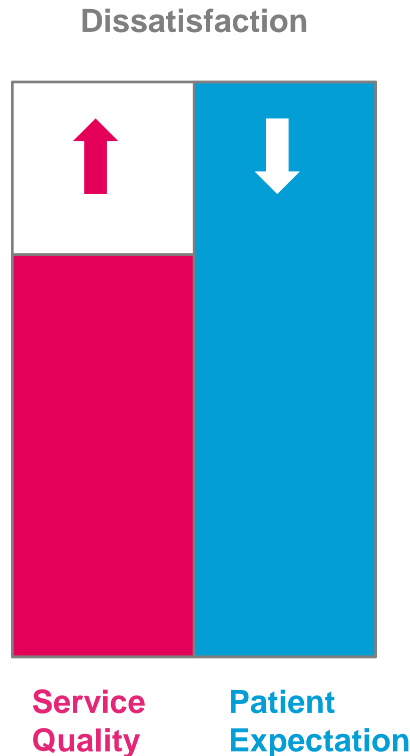
When service quality exceeds expectation we create 'surplus' satisfaction.

PATIENT SATISFACTION

SATISFACTION IS A COMPLEX CONSTRUCT

This has important implications for planning in the context of financial constraints and political imperatives: achieving optimum satisfaction is about managing expectations as well about improving service quality.

In situations where improving service quality is difficult or impossible, satisfaction could still be improved by managing expectations.



Broadly speaking, we have two levers to adjust in order to achieve optimum satisfaction.

1. Improve service quality
2. Manage expectations

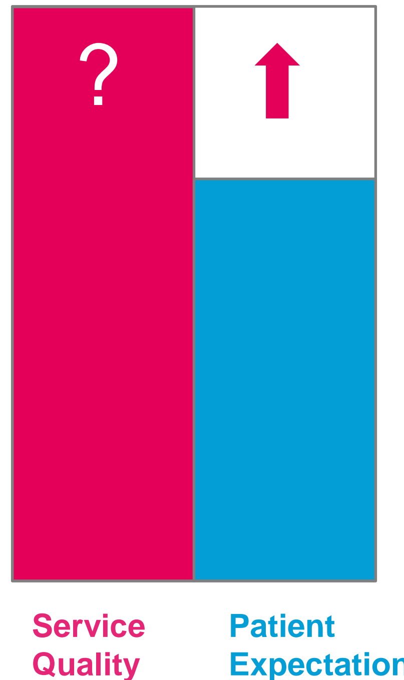
PATIENT SATISFACTION

SATISFACTION IS A COMPLEX CONSTRUCT

This has important implications for planning in the context of financial constraints and political imperatives: achieving optimum satisfaction is about managing expectations as well about improving service quality.

Situations characterised by ‘surplus’ satisfaction could offer opportunities to reprioritise resources.

Surplus satisfaction



Service Quality

Patient Expectation

We have two levers to adjust in order to achieve optimum satisfaction.

1. Improve service quality
2. Manage expectations

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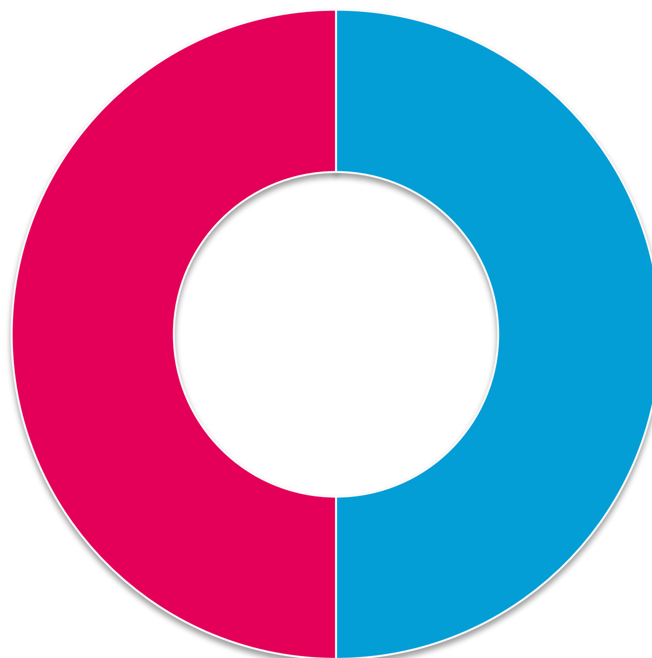
PATIENT SATISFACTION

SERVICE QUALITY IS A COMPLEX CONSTRUCT

Judgements of service quality combine both emotional/spiritual and technical/clinical factors.

EMOTIONAL / SPIRITUAL

Respect and dignity.
Consultation 'manner'.
Time for consultation.
Attentiveness.



TECHNICAL / CLINICAL

Quality / speed of diagnosis.
Waiting times.
Effectiveness of treatment.

"Information and emotional support needs are more important to patients than all other care delivery."[1]

"Compassion with which care is provided has the paramount effect on patients' intentions to recommend/ return."[2]

"Negative evaluations of emotional dimensions of care negatively affected evaluations of technical quality."[3]

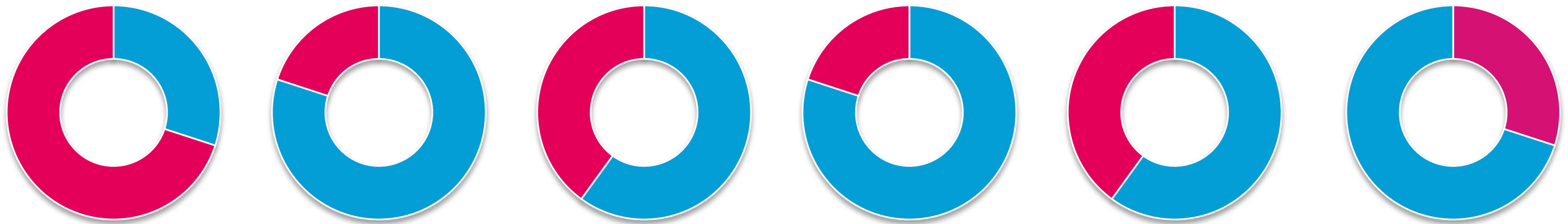
"Patient satisfaction is a summation of all the patient's experiences in the hospital without distinction between service and technical care."[4]

PATIENT SATISFACTION

SERVICE QUALITY IS A COMPLEX CONSTRUCT

EMOTIONAL / SPIRITUAL

TECHNICAL / CLINICAL



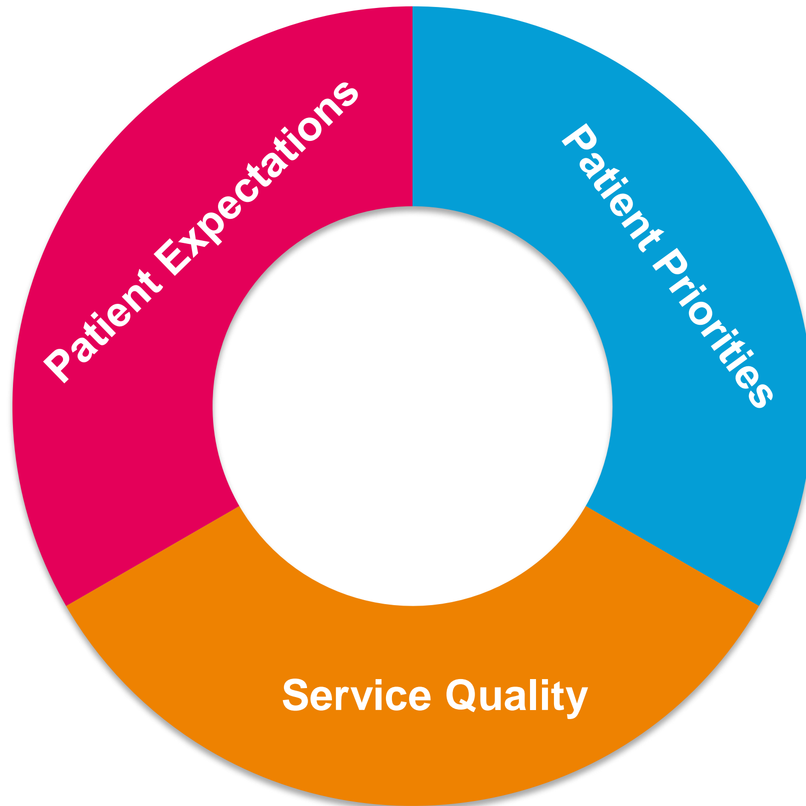
This has important implications for planning in the context of financial constraints and political imperatives: improving service quality is as much about improving interpersonal skills/relationships as it is about improving technical delivery and clinical outcomes.

In situations where emotional / spiritual factors are valued highly, significant, cost-effective impacts on satisfaction could be achieved by improving interpersonal skills / relationships.

More importantly, improvements in the emotional / spiritual domain will increase patient tolerance for any negative change with the technical / clinical domain.

PATIENT SATISFACTION

SATISFACTION IS A COMPLEX CONSTRUCT



Planning for Change

By deepening our understanding of **patient priorities** we can **manage patient expectations and improve service quality** to achieve optimum satisfaction in the context of financial constraints and political imperatives.

3.

UNDERSTANDING SERVICE PRIORITIES

LENS 1

RESEARCH FRAMEWORK

The approach

- Determine the relationship between the key attributes of the service and satisfaction then model the expected impact on satisfaction (see next slide)
- Choice-based data: comparing one feature against another to prioritise resource allocation, rather than simply produce a patient wish list.
- Use the model to evaluate what-if scenarios as part of the planning process, and beyond.

Key attributes – three main themes

- Quality of care (support, consultation/information et al)
- Confidence in diagnosis/outcome (appointment times, key personnel et al)
- Convenience (waiting times, proximity et al)

DATA COLLECTION METHODOLOGY

- Representative sample of the adult (age 16 and over) population across the two CCG areas:
  - 2003 telephone interviews
  - Fieldwork undertaken April-May 2014
  - Quota controlled on gender, age and ethnicity
- Supplementary sample of Asian communities:
  - 200 face-to-face interviews
  - Fieldwork undertaken April-May 2014
  - Representative across the two CCG areas
- Data collection by CSU:
  - 258 interviews at GP surgeries -
  - Data collected on hand-held devices
  - Shortened version of questionnaire
  - 99 online surveys

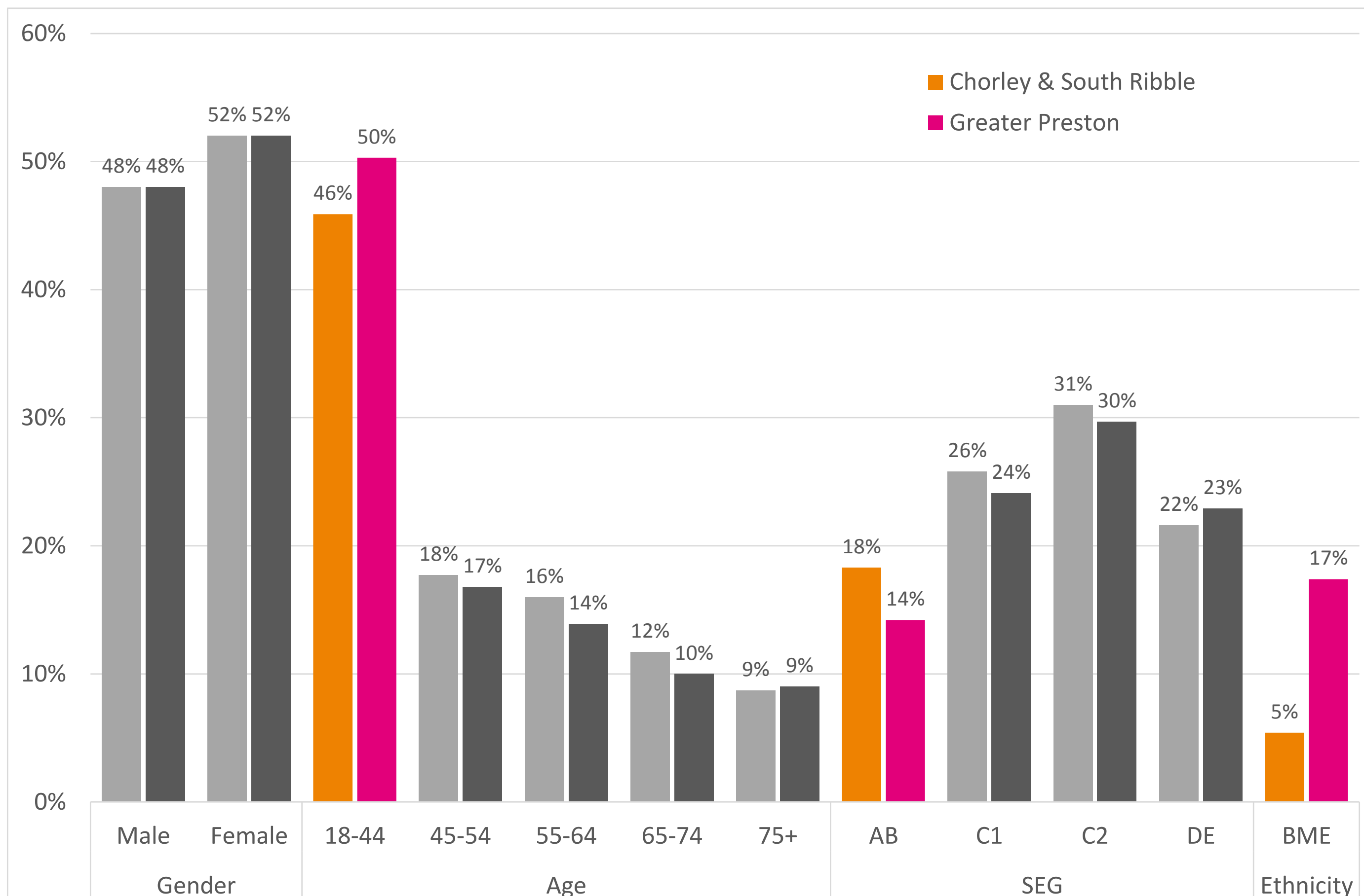
MAP OF SERVICE OPERATIONS TO EXPERIENCE

	Hospital: Planned		Hospital : Emergency		Community Care		GP	
Service points	Hospital is easy to get to	[Priority]	Hospital is easy to get to	[Priority]			GP surgery is easy to get to	[Priority]
					Journey to appointment	[Priority / Satisfaction]		
					Days and times service was available	[Satisfaction]	Days and times service was available for my appointment	[Satisfaction]
	Patient choice	[Priority]			Patient choice	[Priority]	Patient choice	[Priority]
							Service available on evenings & weekends	[Priority]
Clinical personnel	Consultation with medical staff about my diagnosis and treatment	[Priority / Satisfaction]	Consultation with medical staff about my diagnosis and treatment	[Priority / Satisfaction]	Consultation with medical staff about treatment and needs	[Priority / Satisfaction]	Consultation with me about my diagnosis and treatment	[Priority / Satisfaction]
	Reassurance from staff	[Priority / Satisfaction]	Reassurance from staff	[Priority / Satisfaction]	Reassurance from staff	[Priority / Satisfaction]	Reassurance from doctor/nurse	[Priority / Satisfaction]
			Confident in my diagnosis and treatment	[Satisfaction]	Consideration for own needs and beliefs	[Satisfaction]	Confident in my diagnosis and treatment	[Satisfaction]
	Being treat with dignity	[Priority]	Being treat with dignity	[Priority]	Being treat with dignity	[Priority / Satisfaction]		
	I left with all the medication and understanding of my care plan I needed for when I got home	[Satisfaction]	I left with all the medication and understanding of my care plan I needed for when I got home	[Satisfaction]	Help to do things myself in everyday life to improve my condition	[Priority / Satisfaction]		
Delivery	Length of wait to get into hospital	[Satisfaction]			Well organised appointment times	[Priority]	Appointment not being rushed	[Priority]
	The appointment booking process	[Priority / Satisfaction]			Visit not being rushed	[Priority]	Easy appointment booking	[Priority]
	Short waiting time for appointment	[Priority]					Short waiting time for appointment	[Priority / Satisfaction]
	Seeing the same staff each time	[Priority]			Seeing the same staff each time	[Priority]	Seeing the same doctor each time	[Priority]
	Organisation of my admission	[Satisfaction]	Organisation of my admission	[Priority / Satisfaction]				
	My discharge was well planned	[Priority / Satisfaction]	My discharge was well planned	[Priority / Satisfaction]				

3.1

SERVICES
SAMPLE PROFILES

DEMOGRAPHIC PROFILE OF SAMPLE



CCGs largely comparable to each other and Census 2011 figures for England & Wales.

However, CSR has greater proportion from the higher social grades.

GRP has more 18-44 year olds and a notably higher ethnic population (17%, compared to 5% in CSR)

In our GRP sample you are 1.5x more likely to find an adult living alone than in CSR (18% & 13% respectively)

Grey indicates no statistical significance

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

7m households in England are registered as single occupancy; total households = 23m (NomisWeb)

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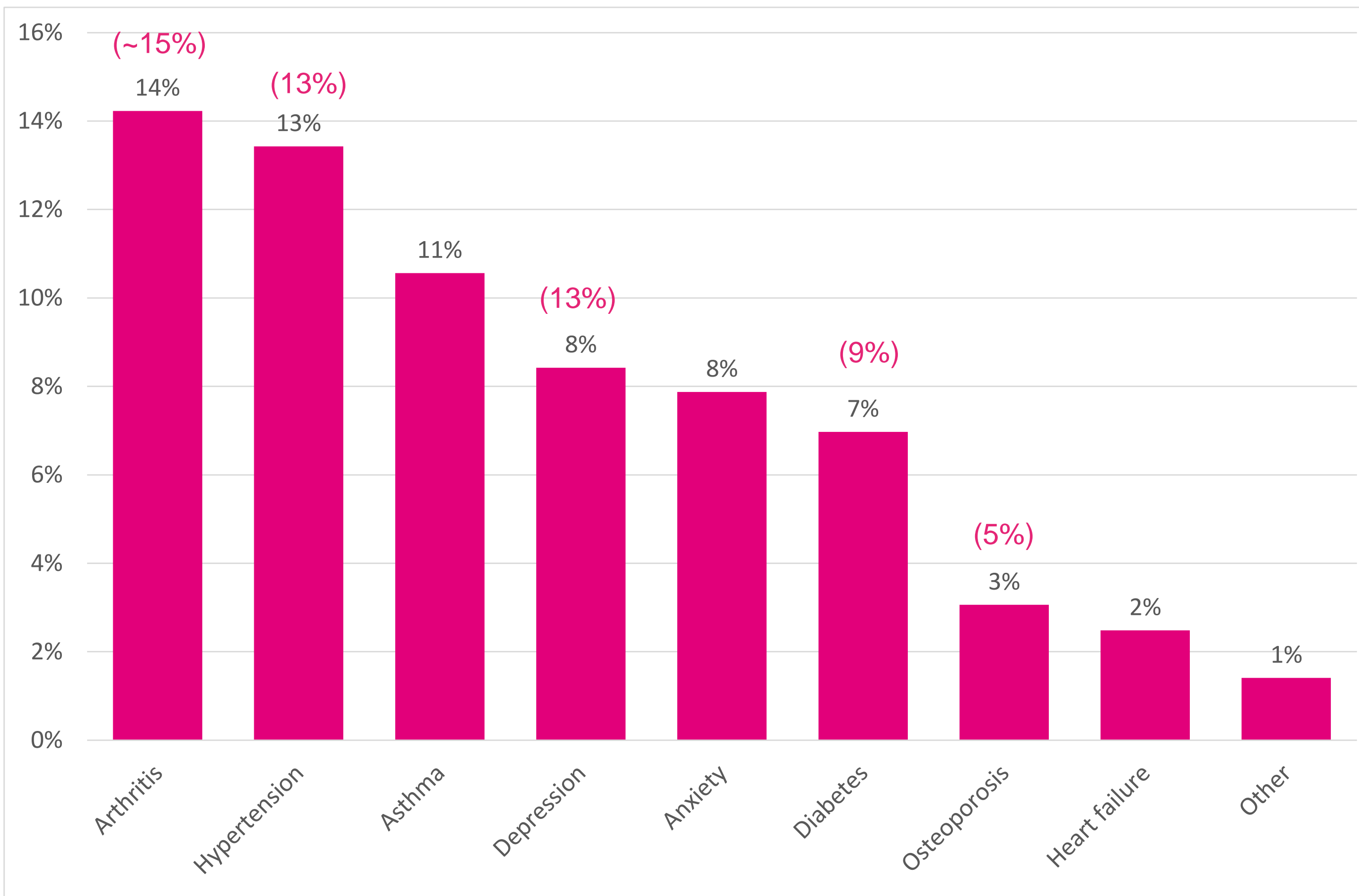
EXISTING LONG-TERM CONDITIONS



58% of sample had no long-term existing medical conditions

Little difference in profile between CCGs

2% of the total sample had previously suffered from a stroke

One in twenty had suffered from some form of cancer.

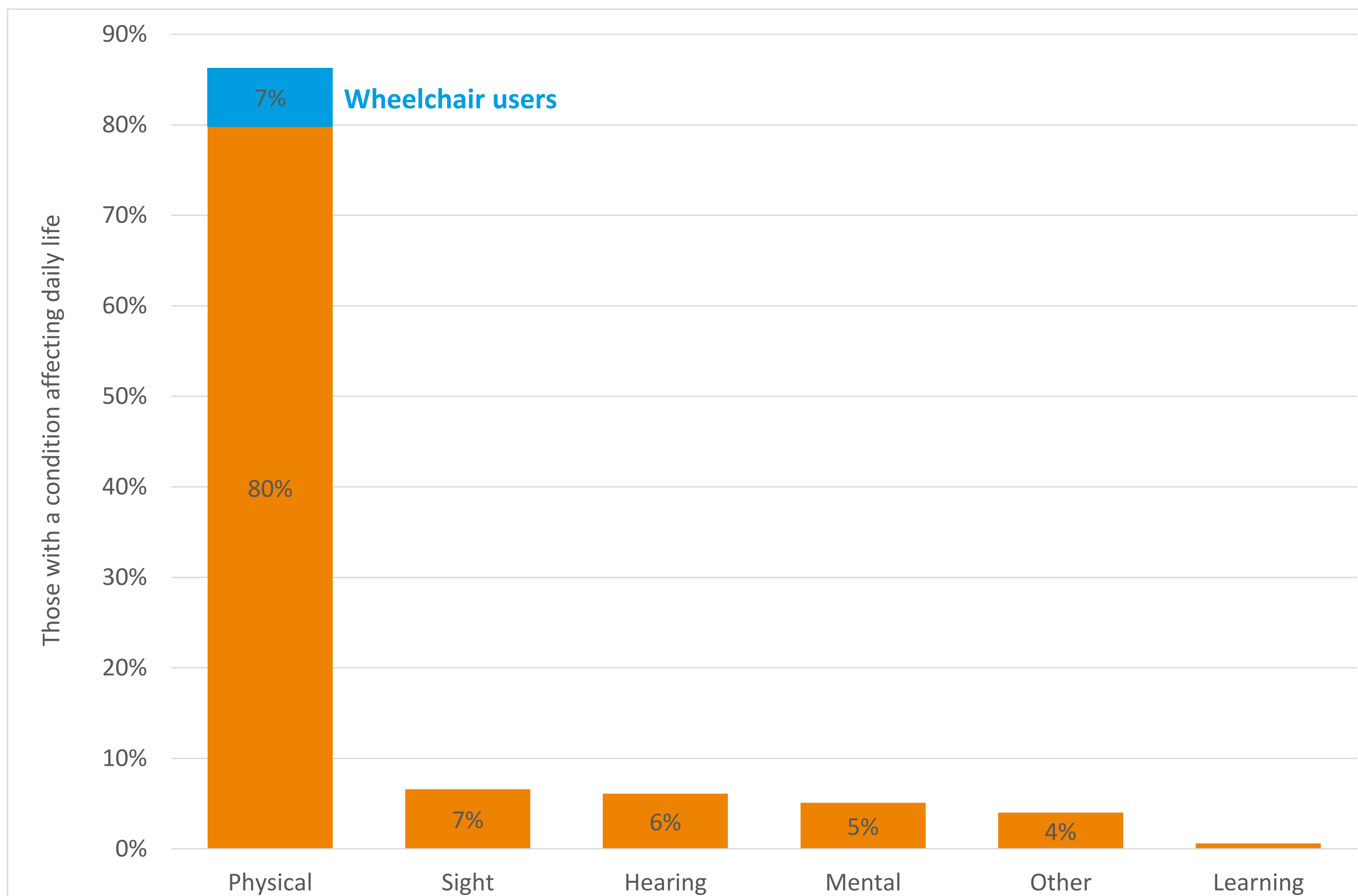
JSNA estimates shown in brackets ()

Q08 Which of the following long-term conditions do you suffer from?

[Prompted]

NEMS

CONDITIONS AFFECTING DAILY LIFE



1 in 5 respondents reported a condition affecting their daily life

The main impairment on everyday life was physical (87%) – of which around 1in 12 were wheelchair users

Respondents from CSR reported higher levels of mental conditions (8% vs 3%)

Sight issues were more prevalent within GRP (9% vs 4%), as was hearing (11% vs 1%)

Q12A Is the condition physical, learning, hearing and/or sight impairment?
CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

Sight problems in UK = 2m; around 365,000 registered blind / partially sighted (NHS Choices)
In the UK, there are an estimated 9 million (out of 63m) deaf and partially hearing people (NHS Choices)

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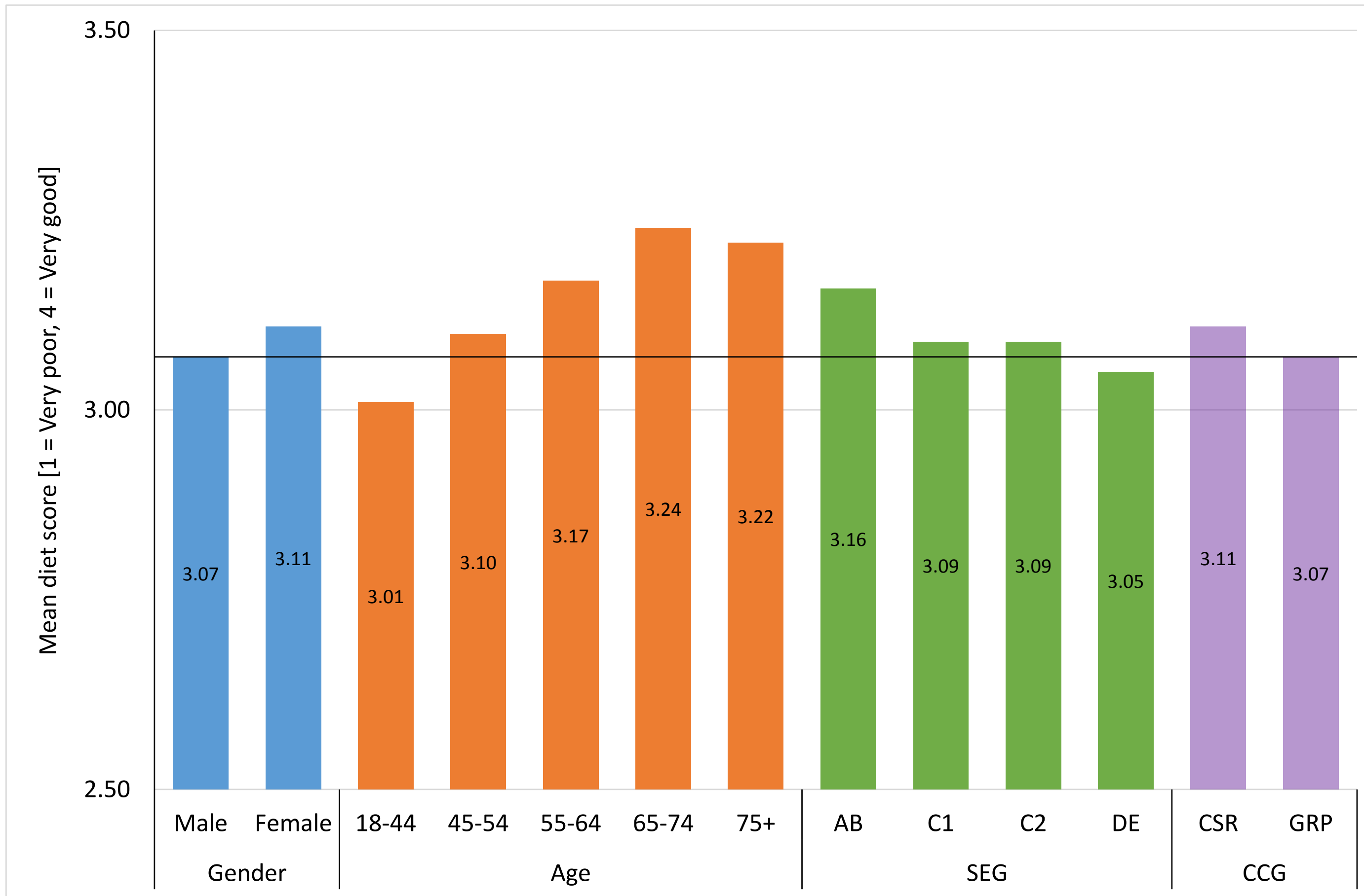
SUPPLEMENTARY DATA COMPARISONS

- **GP surgery data** (258 respondents):
  - Sample profile differences from population –
    - More female
    - More (20%) Indian origin
    - Four times as likely to have a long-term condition affecting daily life
  - 99 respondents asked about planned hospital admission
    - Satisfaction differences (from representative population sample) commensurate with sample profile differences
- **Online data** (91 respondents):
  - Sample profile differences from population –
    - More female
    - All White British
    - More than twice as likely to have a long-term condition affecting daily life
  - Lower overall general satisfaction with NHS services

3.2

SERVICES.
POPULATION OVERVIEW:
LIFESTYLE & CONDITIONS

LIFESTYLE: DIET



Females rated their diet notably greater than men

Diet rating was seen to improve with age

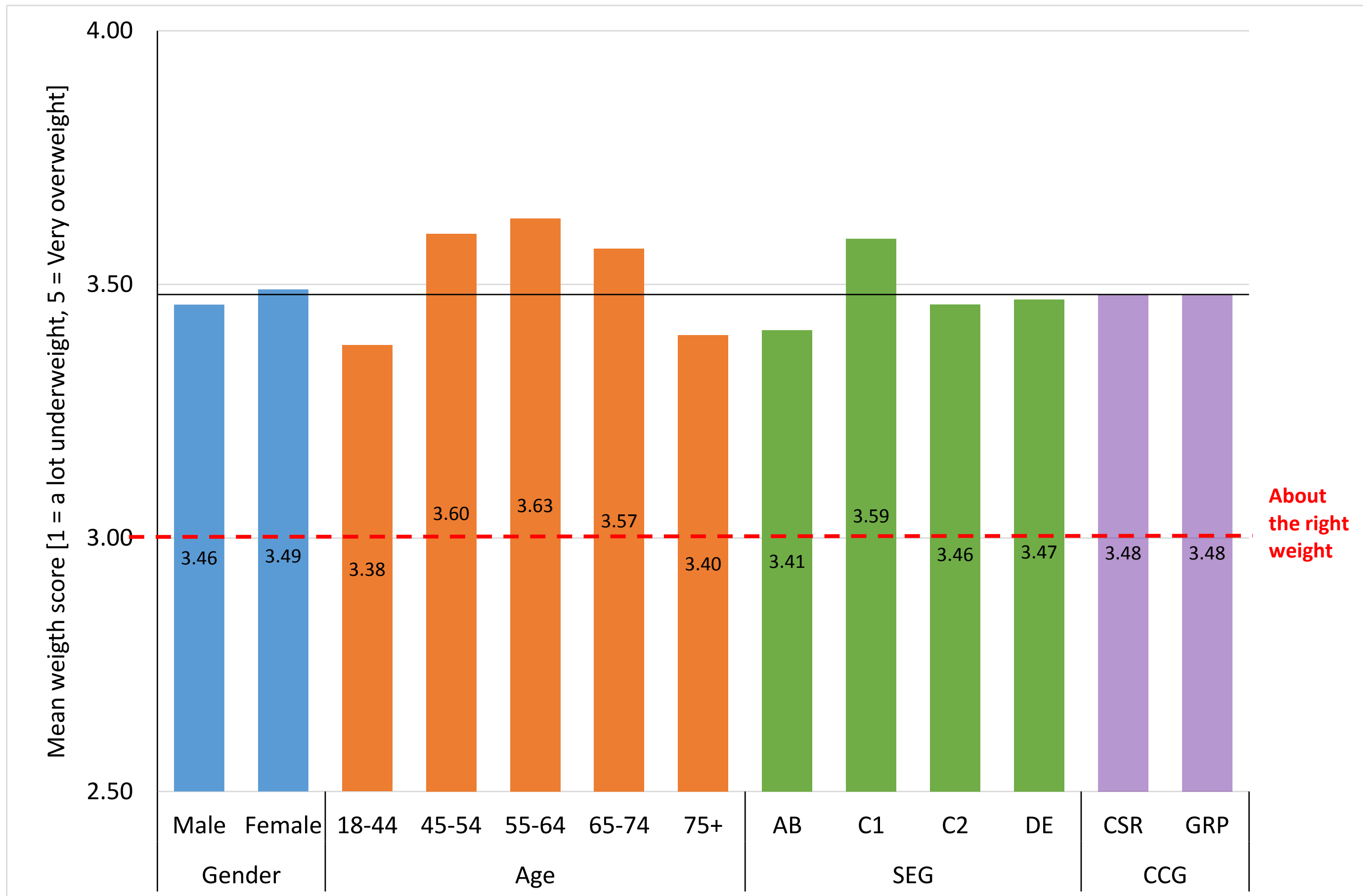
Those from the highest social grading notably rated their diet more than those from the lowest group.

On average, CSR respondents rated their diet notably higher than those from GRP

Axis scale indicates sample average
Q03 How would you describe your diet?
[Prompted Scale]

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

LIFESTYLE: WEIGHT



Very overweight	7%
Little overweight	40%
About right	47%
Little underweight	5%
Very underweight	1%

JSNA 2012/13 excess weight estimate = 63%

Almost half (48%) of those sampled felt they were at the right weight.

On average, all demographic sub-groups felt they were overweight

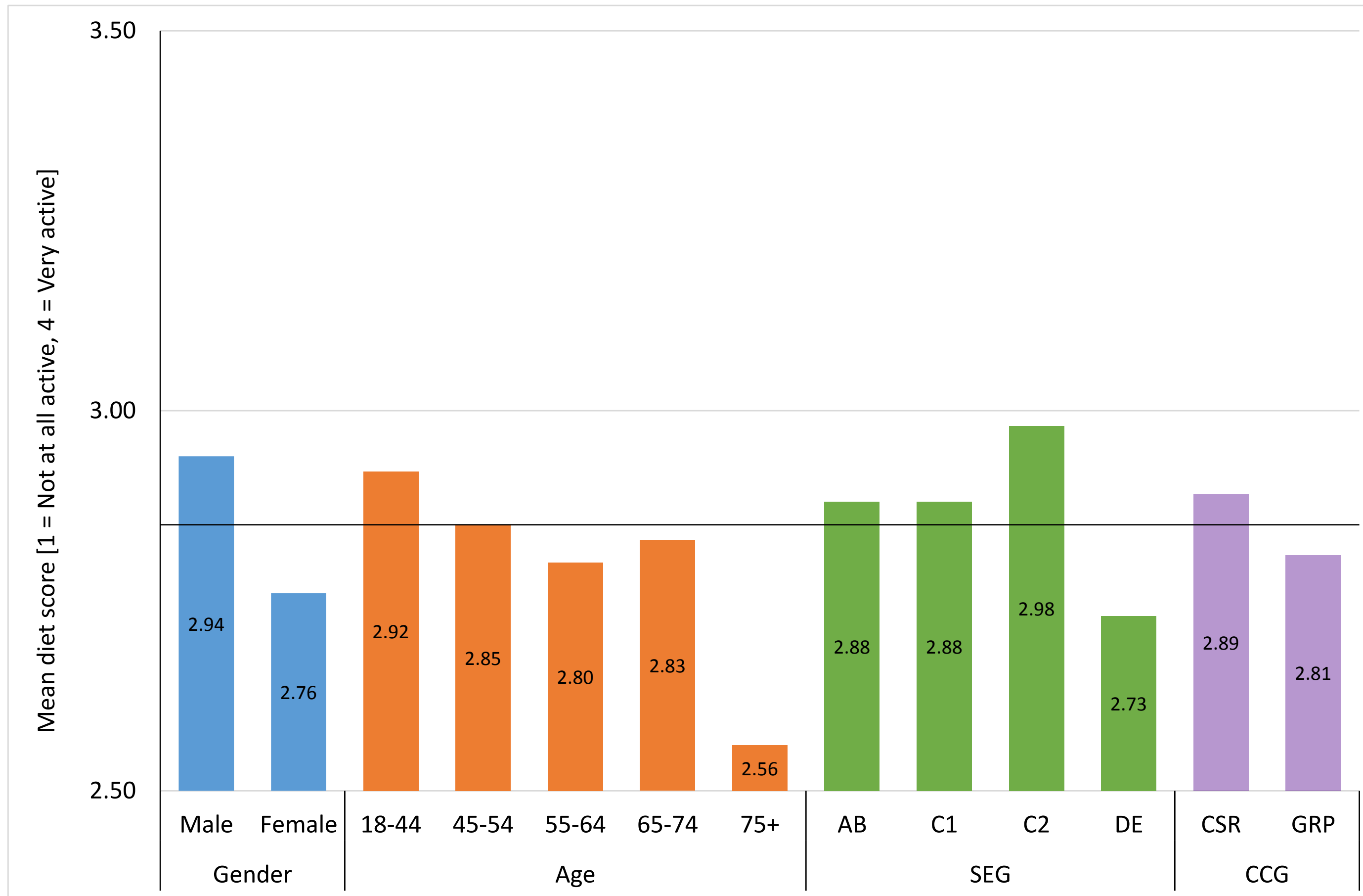
Strongest feeling of being overweight was among 45-74 year olds and those from the C2 social grade.

No difference in opinion was recorded between CCGs

Axis scale indicates sample average
Q03 For your height, would you say that your weight is…?
[Prompted Scale: A lot underweight = 1, Very overweight = 5]

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

LIFESTYLE: PHYSICAL ACTIVITY



72% considered themselves to be physically active, while 1 in 20 answered not at all

Men were notably more active than women, and activity was seen to decrease with age – most notably among those 75+

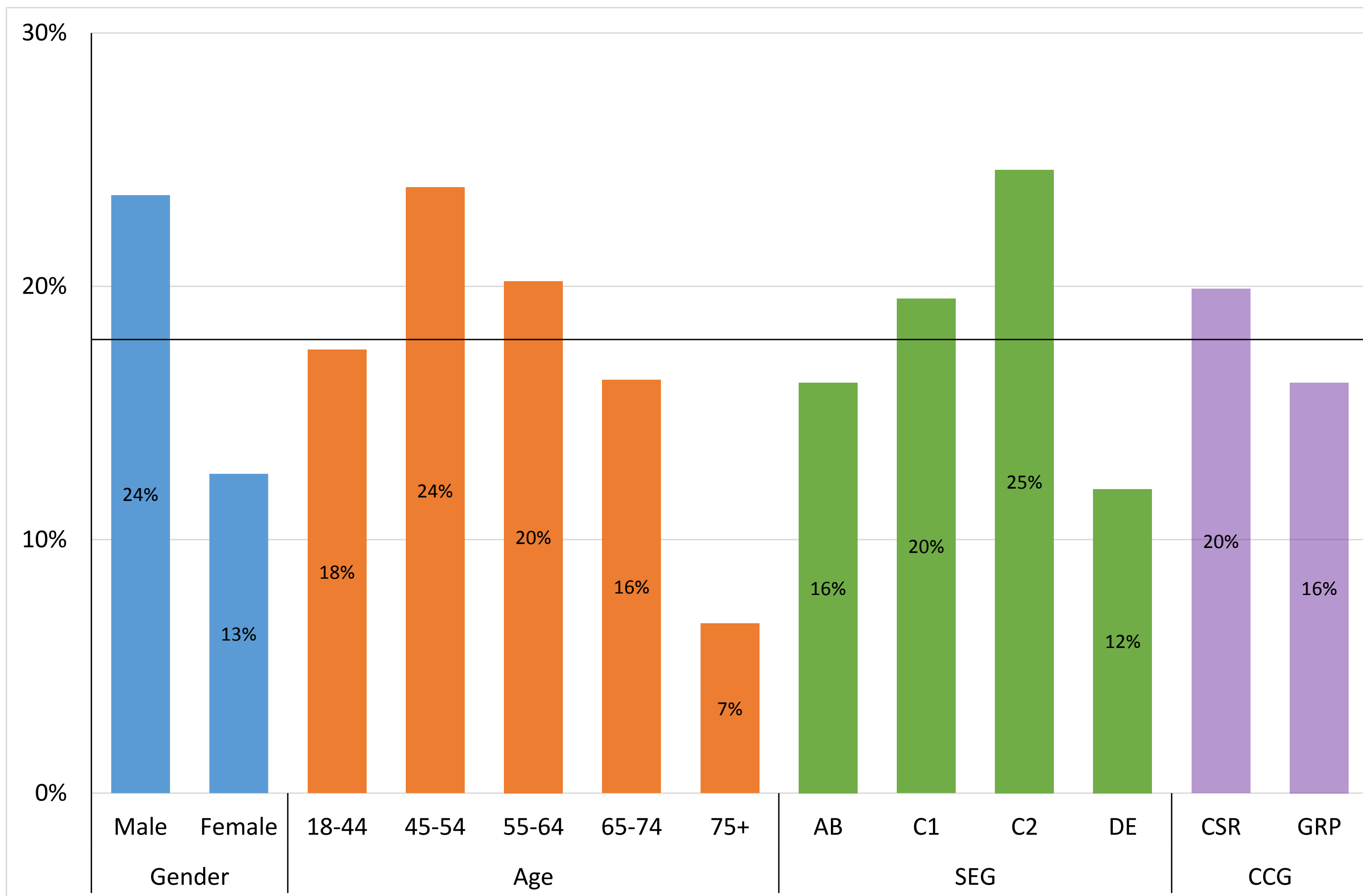
The C2 social grade considered themselves to be the most active, while DE's came out as least active.

CSR was notably more active than GRP.

Axis scale indicates sample average
Q04 Which of the following best describes your level of activity? This might include activity at work, home or leisure. [Prompted Scale: Not at all physically active = 1, Very physically active = 4]

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

LIFESTYLE: ALCOHOL CONSUMPTION LEVELS



Around a quarter didn't drink alcohol – higher than JSNA 2011 estimates

43% drank below the recommended level, while 18% admitted to drinking more than the recommended amount.

Males, those aged 45-54 and from the C1 / C2 social grading were most likely to have consume alcohol above recommended levels.

Axis scale indicates percentage above recommended limit
Q05 Compared to the recommended weekly limit for {men/women}, how much alcohol do you normally drink?
[Prompted Scale: A lot less = 1, Recommended amount = 3, A lot more = 5]

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

	JSNA Est 2011 %		Survey %
Abstain	13	Do not drink	26
Lower	56	Less/about rec. limit	56
Increasing	24	A little more	12
Higher	8	A lot more	6

LIFESTYLE: SMOKING PREVALENCE

	Total	Male	Female	18-44	45-54	55-64	65-74	75+	AB	C1	C2	DE	CSR	GRP
		Gender		Age					SEG				CCG	
Ever smoked	32%	38%	27%	25%	29%	38%	43%	49%	28%	34%	32%	32%	33%	31%
Current smoker	20%	19%	20%	27%	16%	12%	13%	8%	8%	19%	24%	25%	21%	19%

20% current smokers *(JSNA 2011 estimate = 20%)*

More than half of the sample have smoked, with 6 out of ten smokers quitting the habit.

The habit of smoking was most common among men, those aged 65+ and those in the lower social grading's.

However, those aged 18-44 are most likely to be current smokers, with the majority of smokers in older ages having quit the habit.

Q05 Have you ever smoked?
Q06 Do you still smoke?

CSR [Chorley & South Ribble CCG], GRP [Greater Preston CCG]

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POOR LIFESTYLE HABITS: SUMMARY

	Male	Female	18-44	45-54	55-64	65-74	75+	AB	C1	C2	DE
Poor diet	10%	8%	12%	8%	5%	4%	4%	7%	7%	**11%**	**12%**
Very overweight	6%	7%	5%	9%	9%	7%	49%	3%	**9%**	6%	**9%**
Not at all physically active	4%	6%	3%	4%	6%	**8%**	**12%**	2%	3%	4%	**9%**
Drink more than recommended	**24%**	13%	18%	**24%**	**20%**	16%	7%	16%	**20%**	**25%**	12%
Current smoker	19%	20%	**27%**	16%	12%	13%	8%	8%	19%	**24%**	**25%**

- C2DEs are most likely to have poorer lifestyle habits
- Men and women share similar lifestyle traits – except for alcohol, where there is almost twice the prevalence of heavy drinkers.
- Likelihood of quitting smoking increases with age, as does physical inactivity.

Red cells indicate greater prevalence of poor lifestyle habits

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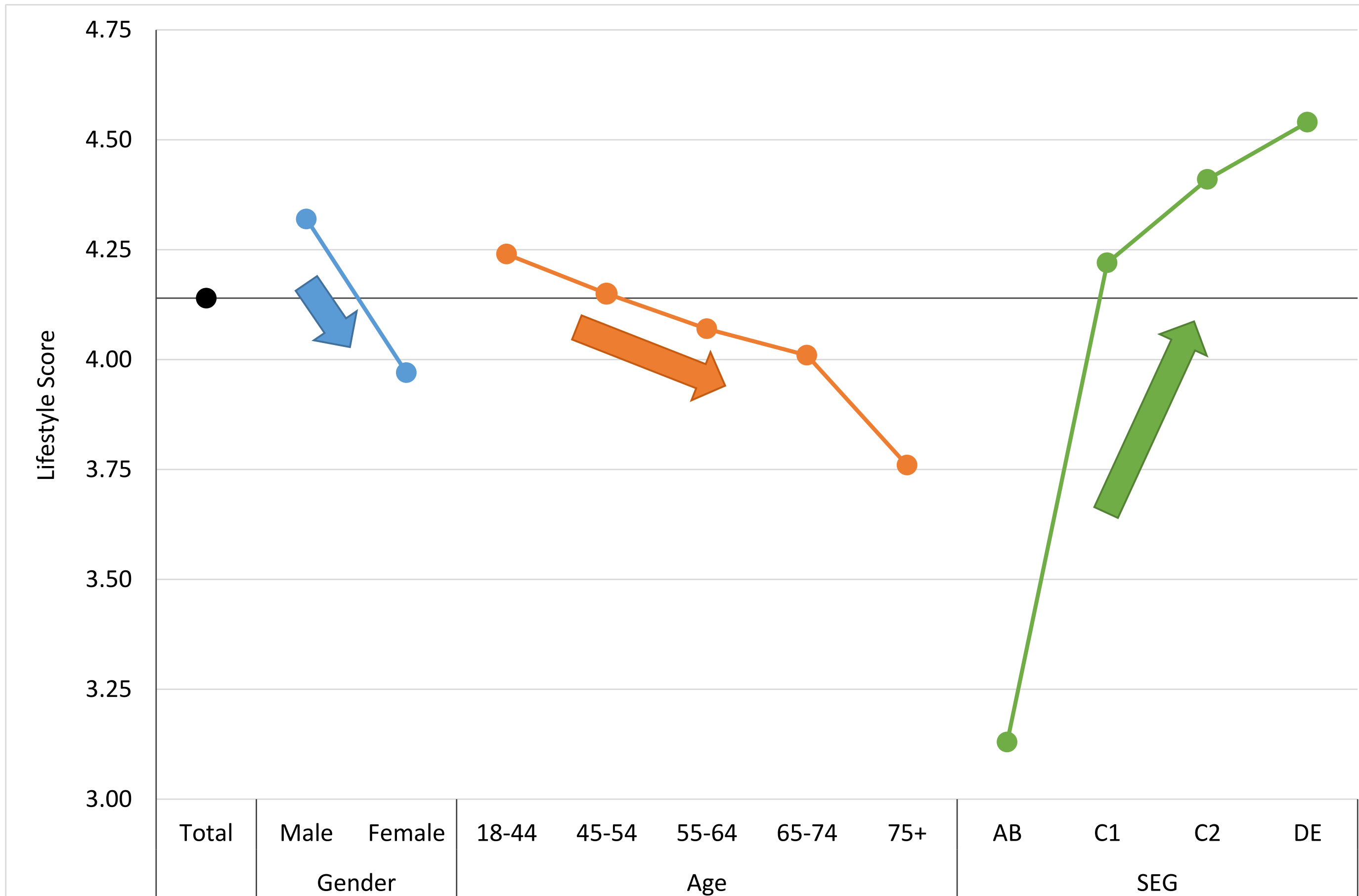
COMPOSITE LIFESTYLE SCORING

- To better classify respondents on their lifestyle habits, a scoring system was applied to the following lifestyle attributes:

Attribute	Scoring
Diet {good or poor}	Quite good = 1 Quite poor = 2 Very poor = 4
Weight {overweight or underweight}	Very over/under = 4 Little over/under = 1
Physical activity	Not very = 1 Not at all = 4
Alcohol consumption	A lot more = 4 A little more = 2 About rec limit = 1
Smoking prevalence	Ever smoked = 2 Currently smoke = 4

- Points were awarded for each negative lifestyle response, with a minimum of zero (indicating no poor lifestyle habits) and a maximum of 20; the greater the number the poorer the lifestyle.

LIFESTYLE: COMPOSITE SCORING



Women have a better composite lifestyle score than men

Lifestyle score improves with increasing age – habits such as smoking become less prevalent

AB shows a markedly better lifestyle score than other socio-economic groups

Axis point indicates sample average
Based on a scoring system for responses from Q02 to Q07, with the minimum being 0 and the max score being 20.

The higher the score the poorer the lifestyle habit.

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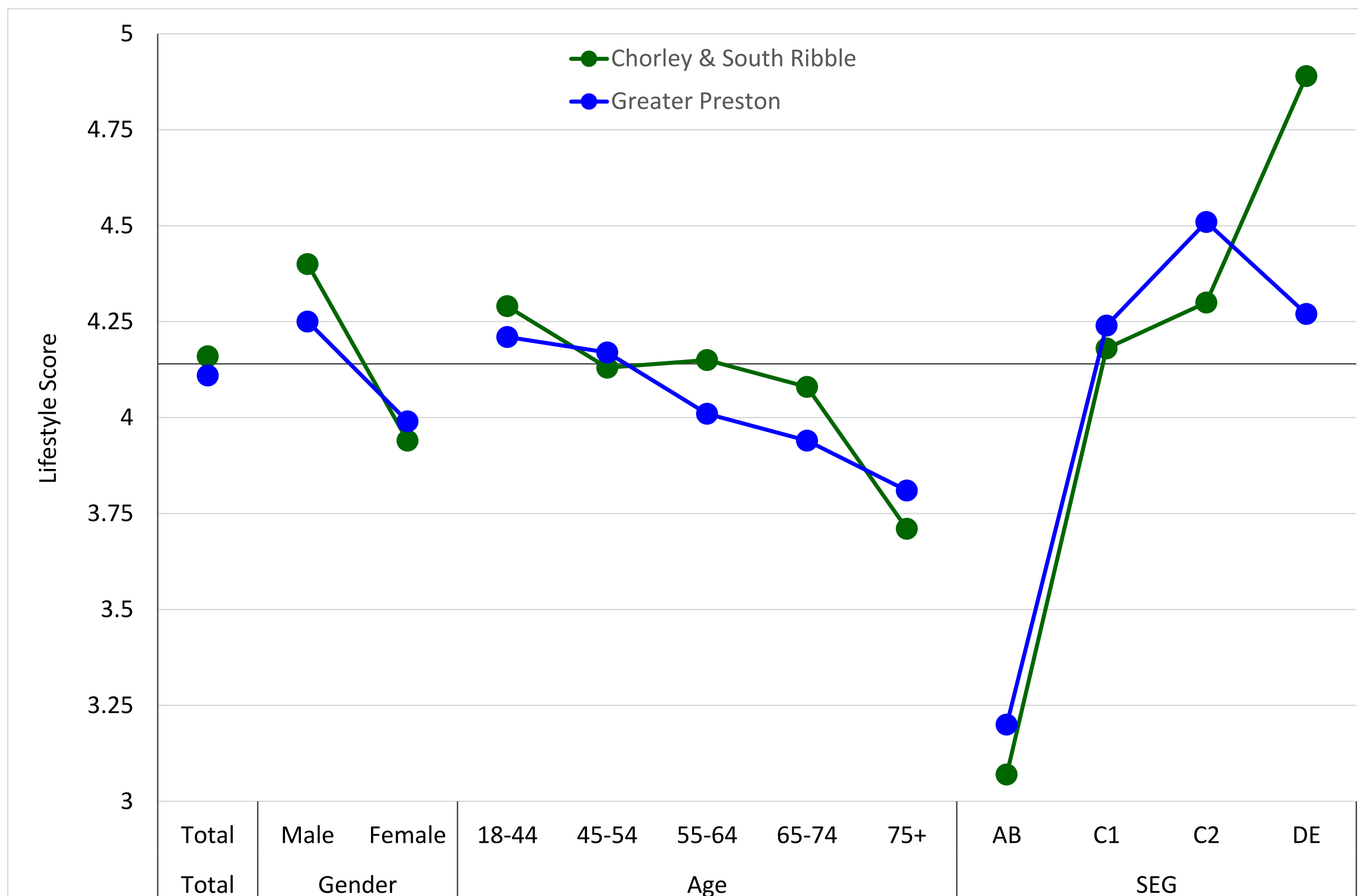
LIFESTYLE: COMPOSITE SCORING CCGs



Composite lifestyle score among DE's notably better in Greater Preston:

Difference due to larger BME population who show a lower propensity for smoking and alcohol consumption

Axis point indicates sample average
Based on a scoring system for responses from Q02 to Q07, with the minimum being 0 and the max score being 20.

The higher the score the poorer the lifestyle habit.

NEMS

LIFESTYLE DEMOGRAPHIC SEGMENTATION

Composite lifestyle score (LFS)

Condition affects daily life

No (23%)

Yes (41%)

Depression / anxiety

No (21%)

Yes

Diabetes

No (38%)

Yes

Gender

Male

Female

Ethnicity

White British

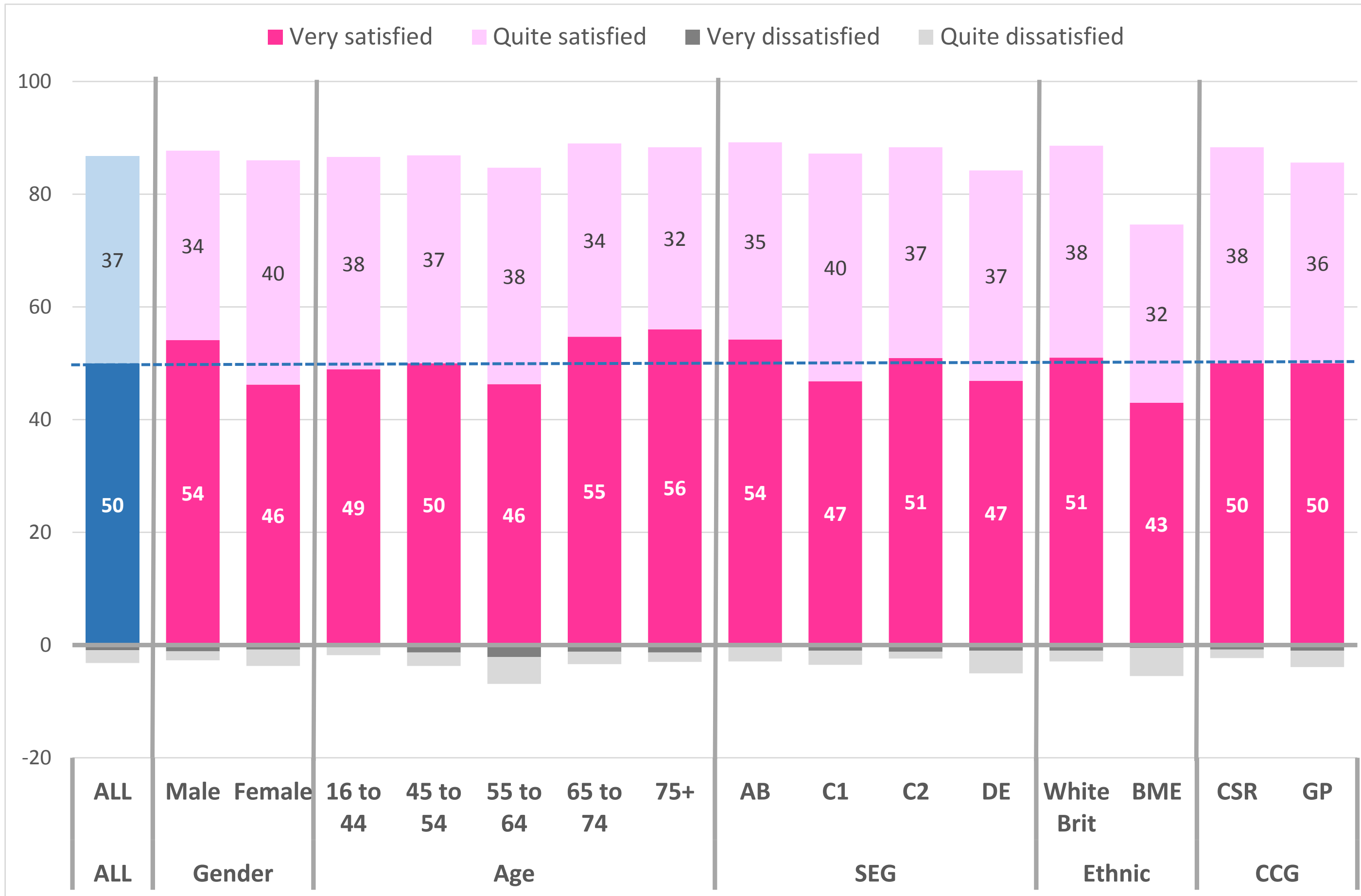
BME

Segment 1	Segment 2	Segment 3	Segment 4	Segment 5	Segment 6
36%	37%	7%	16%	2%	4%
25% LFS>5	17% LFS>5	46% LFS>5	41% LFS>5	11% LFS>5	57% LFS>5

3.3

SERVICES
SERVICE SATISFACTION

SATISFACTION OVERVIEW: GENERAL



87% satisfied overall with services (compared with 70% nationally[1])

Men more satisfied than women

Satisfaction tends to increase with age

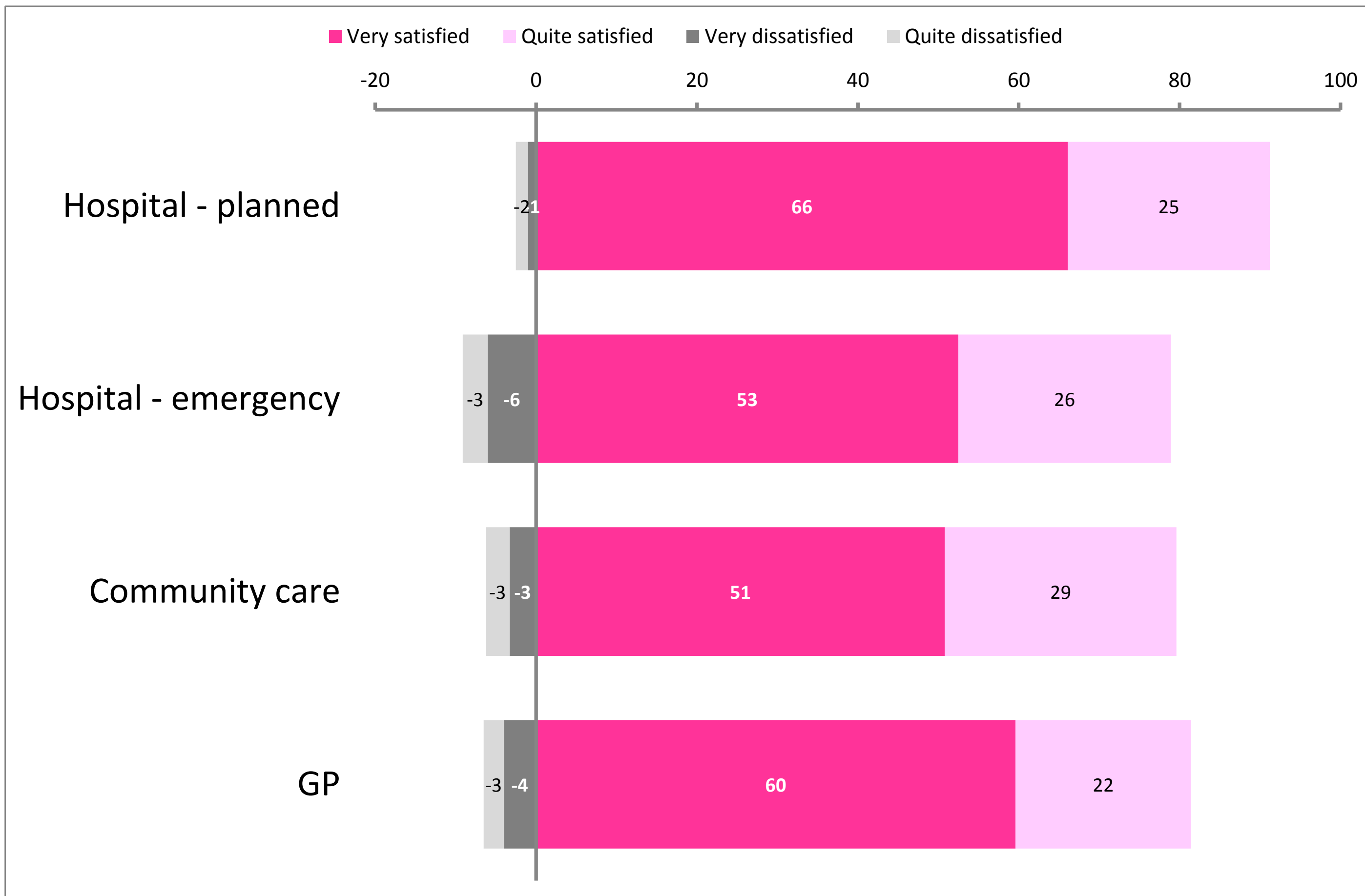
White British more satisfied than BMEs

Q52 Thinking generally about the NHS, how satisfied are you overall with the health services they provide?

[1] *Public perceptions of the NHS and social care, December 2011. IPSOS MORI Social Research Institute*

NEMS

SATISFACTION OVERVIEW: EPISODE



For any type of episode:

58% were very satisfied;
6% were dissatisfied

GP satisfaction lower for more recent visits:

More than a year ago, mean = 4.47
Within last year, mean = 4.37
Within last 3 months, mean = 4.18

Episode satisfaction compared against overall general satisfaction with health service;

About a third higher and a third lower ->

Will result in a very fluid overall satisfaction rating with a constantly high level of change

Q36, Q28, Q49 and Q43
Thinking about the overall experience, how satisfied were you with the service you received?

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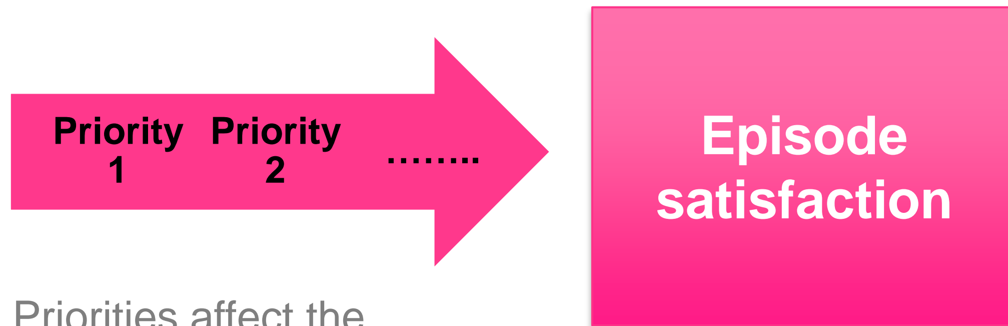
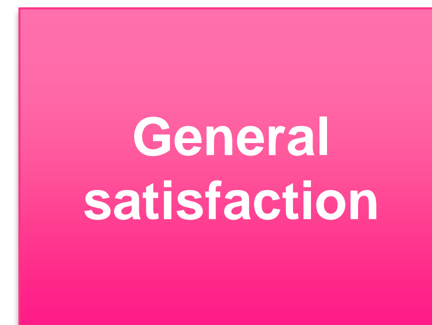
IMPACT OF PRIORITIES ON SATISFACTION



Priorities affect the impact of attribute satisfaction on episode satisfaction – The lens through which the experience is viewed

Episode increments overall general satisfaction



Strong inter-relationship between attribute satisfaction measures

Priorities are more a personality trait than defined by lifestyle and circumstances

PRIORITY MAPPING

Each service sub-section in the analysis that follows concludes with a ‘priority map’.

These have been designed to aid planning through a clear visual representation of what action is required in relation to particular service attributes and the importance that this has in relation to patient satisfaction.

Based on these ‘maps’, it will possible to highlight service attributes that we need ***Protect, Improve, Review or Monitor*** and understand how urgent the action is.

The maps are divided into 4 areas, as per the key in the top right hand corner of this slide. The following slide provides a key that explains the significance of each area.

SERVICE ATTRIBUTES: PRIORITY & SATISFACTION

REVIEW

Low priority / high satisfaction = Moderate importance

These are areas that are less important to patients, but in which we are performing well. This quadrant could represent a less significant source of satisfaction and could offer opportunities to re-prioritise resource . Changes that affect service quality in these areas may not have a significant impact on patient satisfaction and therefore could represent opportunities for cost-saving. As such, we should review these areas as part of the planning process.

PROTECT

High Priority / High Satisfaction = Moderate-High importance.

These are areas that are important to patients and in which we are currently performing well. This quadrant represents our most significant source of *satisfaction*. Changes that reduce service quality in these areas could significantly *reduce* patient satisfaction. As such, we should plan to protect these areas.

MONITOR

Low priority / low satisfaction = Low importance

These are areas that are less important to patients, but in which are under performing. This quadrant represents a less significant source of dis-satisfaction. Improvements in service quality in these areas are unlikely to significantly increase satisfaction and therefore are unlikely to delivery the greatest value for money. As such, we should plan to monitor these areas to ensure that satisfaction, although low, does not reduce further.

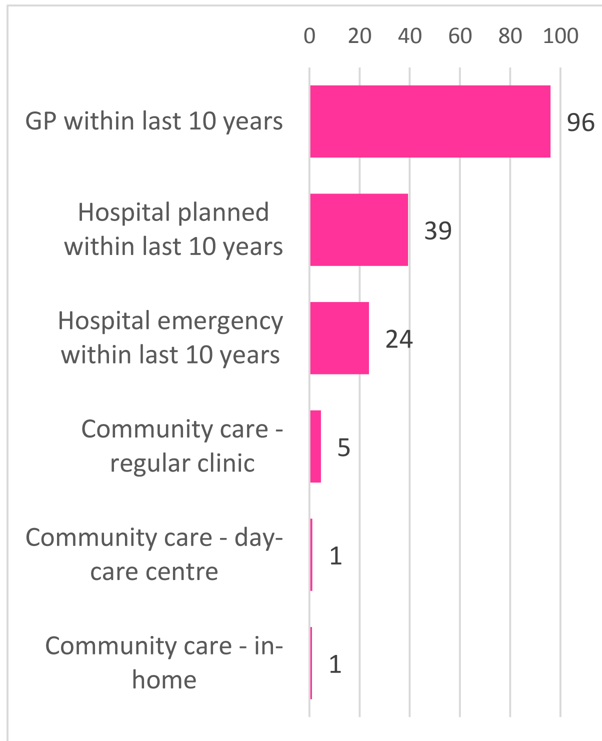
IMPROVE

High priority / low satisfaction = High importance

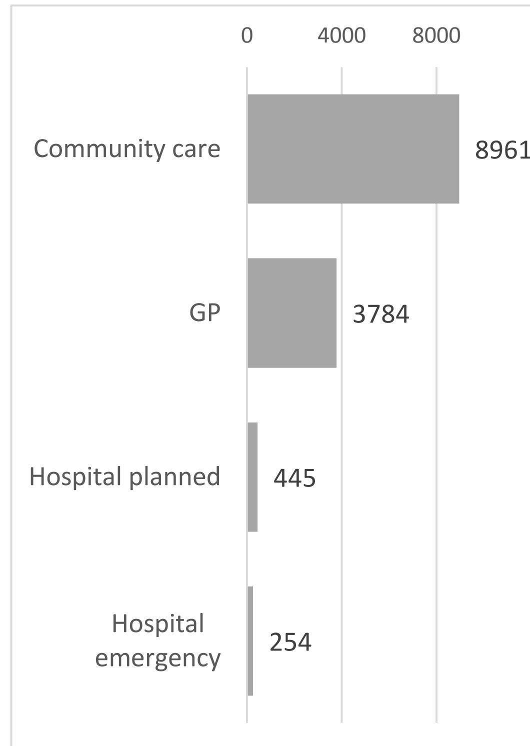
These are areas that are important to patients, but in which we are currently under-performing. This quadrant represents our most significant source of *dis-satisfaction*. Changes that improve service quality or manage expectations in these areas could significantly *increase* patient satisfaction. As such, we should plan to improve these areas.

SERVICE USAGE

Percentage of population who use different services:



Estimated annual episodes per 000 respondents:



GP is most widely used service

However, general satisfaction is most likely to change when an episode occurs

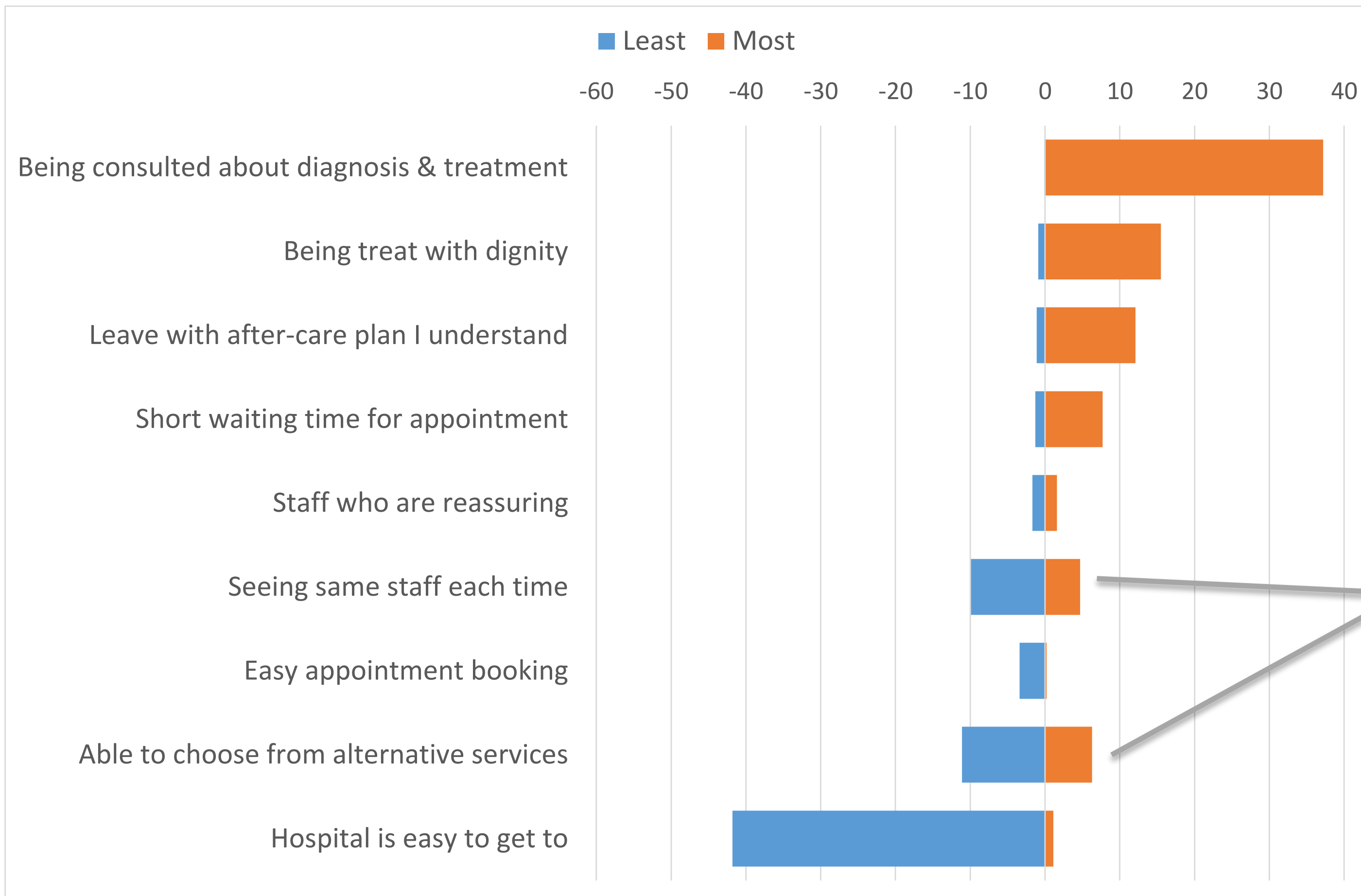
Biggest impact on overall satisfaction can be expected where high numbers of episodes occur

3.4

SERVICE PRIORITIES: HOSPITAL (PLANNED)

SUBSAMPLE: 472 RESPONDENTS

HOSPITAL (PLANNED) PRIORITIES



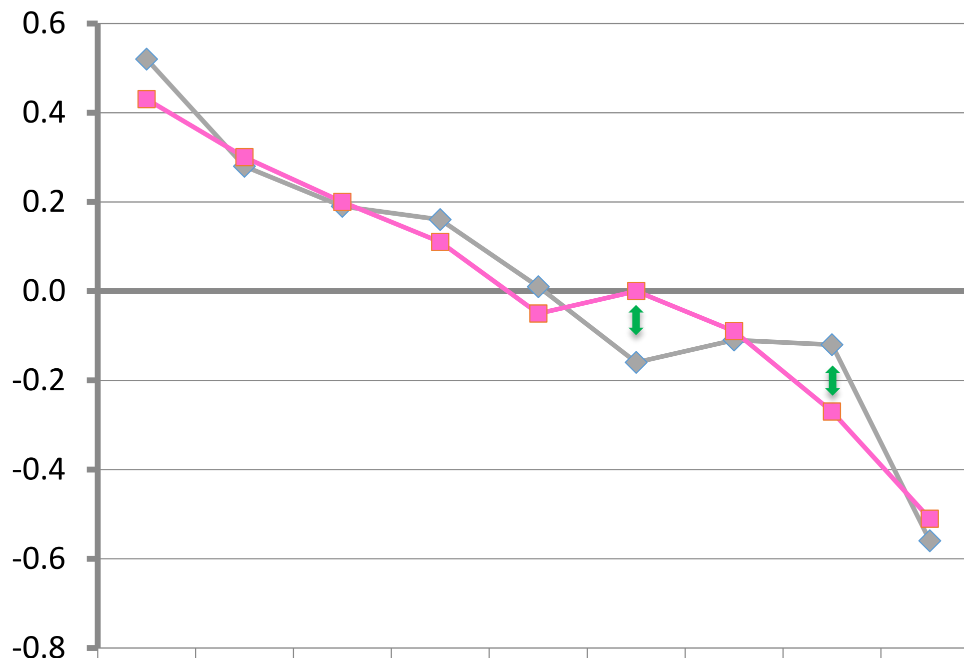
Priorities differ between attributes

Some attributes show extreme views at both ends of the spectrum: most important for some and least important for others

Q51 Priority ranking of service attributes

Attribute ranking as percentage most and least important

HOSPITAL (PLANNED) PRIORITIES



	A	B	C	D	E	F	G	H	I
Chorley & S Ribble	0.5	0.3	0.2	0.2	0.0	-0.2	-0.1	-0.1	-0.6
Greater Preston	0.4	0.3	0.2	0.1	-0.1	0.0	-0.1	-0.3	-0.5

Priority mix broadly similar for the two populations in the two CCG areas

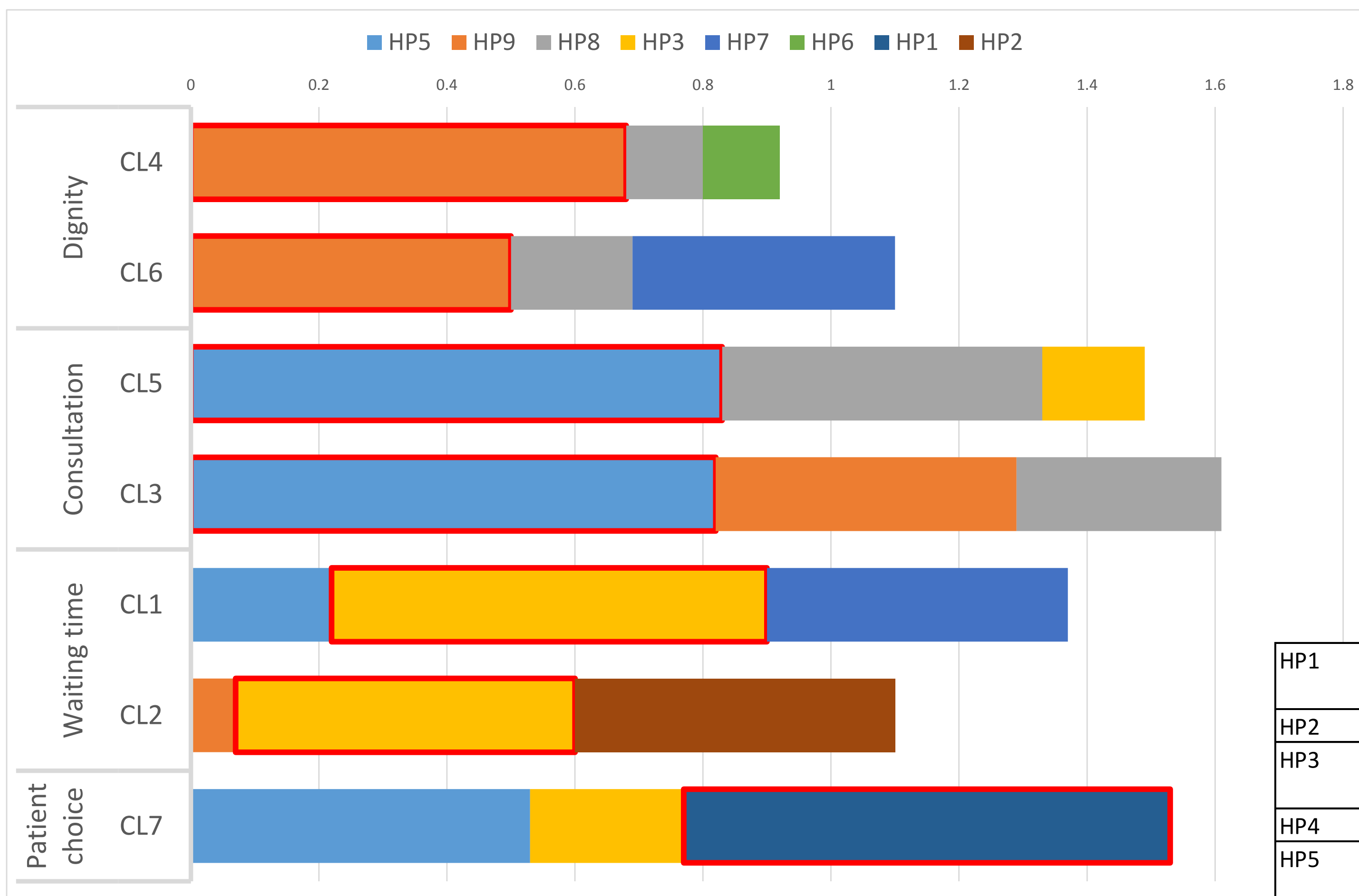
Slight differences on 'seeing same staff each time' and 'able to choose from alternative services'

A	Being consulted about diagnosis & treatment
B	Being treat with dignity
C	Leave with after-care plan I understand
D	Short waiting time for appointment
E	Staff who are reassuring
F	Seeing same staff each time
G	Easy appointment booking
H	Able to choose from alternative services
I	Hospital is easy to get to

Q51 Priority ranking of service attributes

Mean attribute ranking

‘PRIORITY’ SEGMENTS (top 3 priorities)



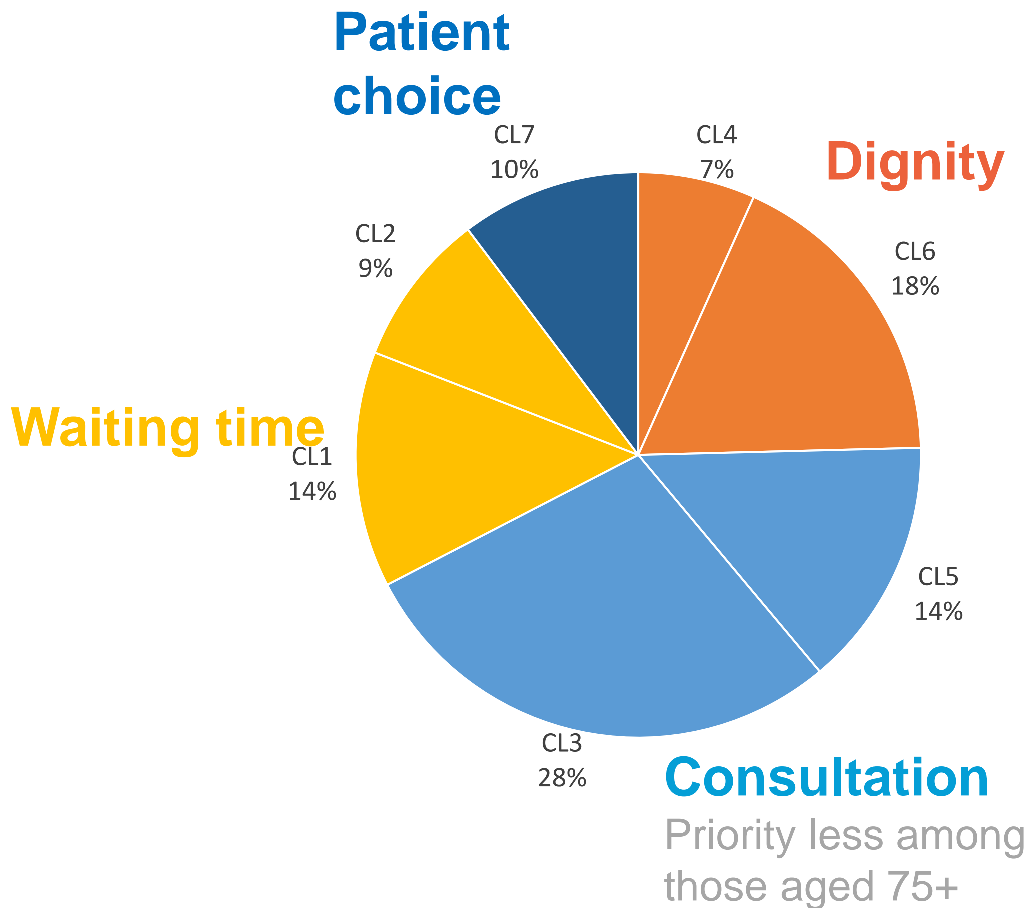
Overall sample priorities hide diversity of opinion

Groups in the population with clearly different priorities

HP1	Being able to choose from alternative services
HP2	Hospital is easy to get to
HP3	Short waiting time for appointment
HP4	Easy appointment booking
HP5	Being consulted about my diagnosis and treatment
HP6	Staff who are reassuring
HP7	Seeing the same staff each time
HP8	Leaving with an after-care plan I understand
HP9	Being treat with dignity

NEMS

HOSPITAL PLANNED: 'PRIORITY' SEGMENTS



Consultation

Priority less among those aged 75+

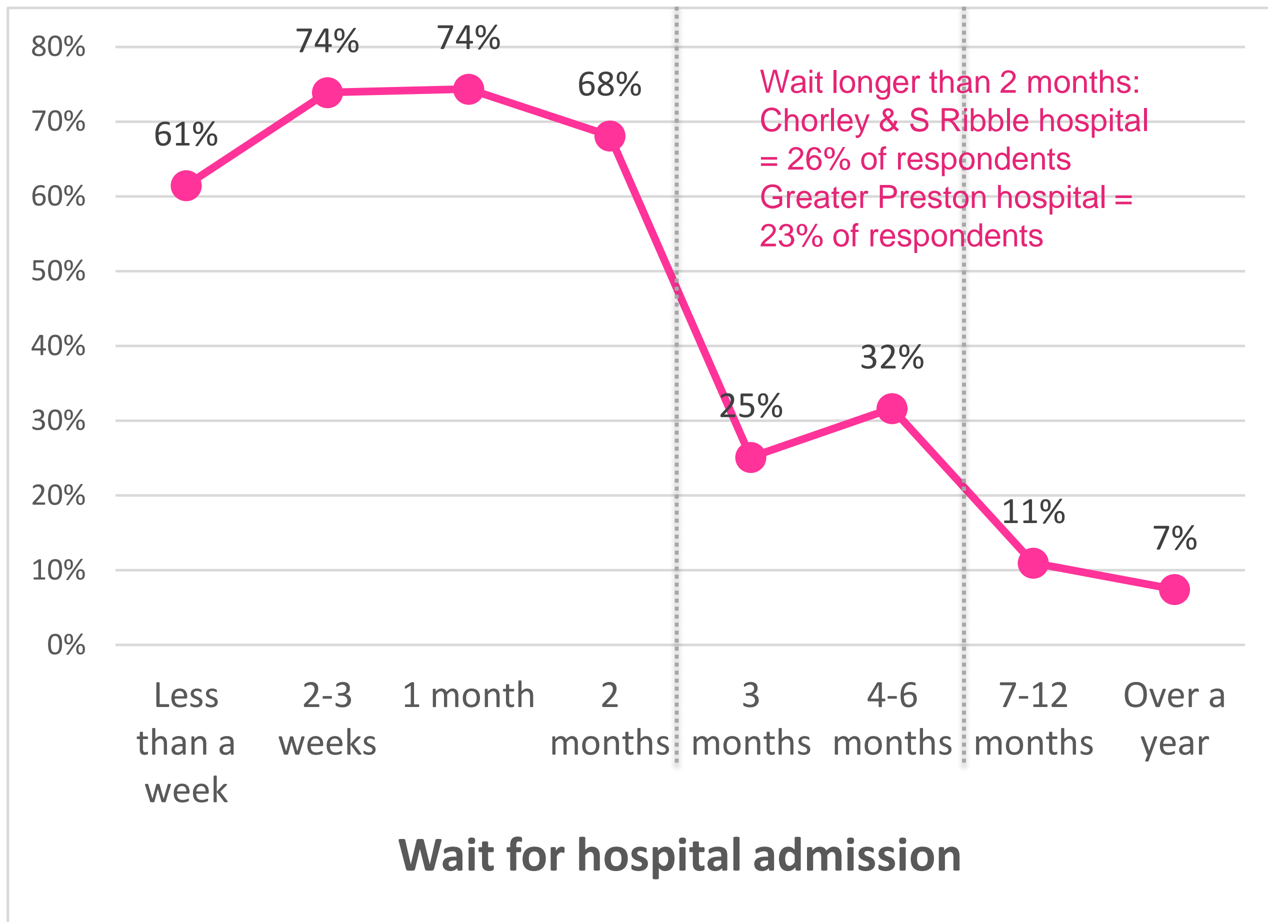
Relative sizes of the different priority segments and any notable demographic differences

Mix differs a little between CCGs

	CSR	GP
Consultation	48%	38%
Waiting time	21%	24%
Dignity	20%	30%
Patient choice	12%	9%

IMPACT OF WAITING TIMES ON SATISFACTION

Percentage very satisfied with length of wait to get into hospital:



Two clear 'trigger' points for large fall in satisfaction:

> 2 months

> 6 months

Q31 How long did you have to wait to get your hospital appointment/admission?

Q35 Thinking about your experience, how satisfied were you with each of the following? *Length of wait to get into hospital*

EPISODE SATISFACTION

Very satisfied | Quite satisfied | Very dissatisfied | Quite dissatisfied

	Quite dissatisfied	Very dissatisfied	Very satisfied	Quite satisfied
Length of wait to get into hospital	-5	1	58	28
The appointment booking process	-2	1	62	26
Organisation of my admission	-2	1	66	27
Consultation with medical staff about my diagnosis and treatment	-1	1	71	23
Reassurance from staff	-3	1	68	24
My discharge was well planned	-3	-7	58	27
I left with all the medication and understanding of my care plan I needed for when I got home	-2	2	67	22
OVERALL EPISODE	-2	1	66	25

Axis: -20, 0, 20, 40, 60, 80

Affected by actual wait:
Impact increases rapidly after approx. 2 and then 6 month wait

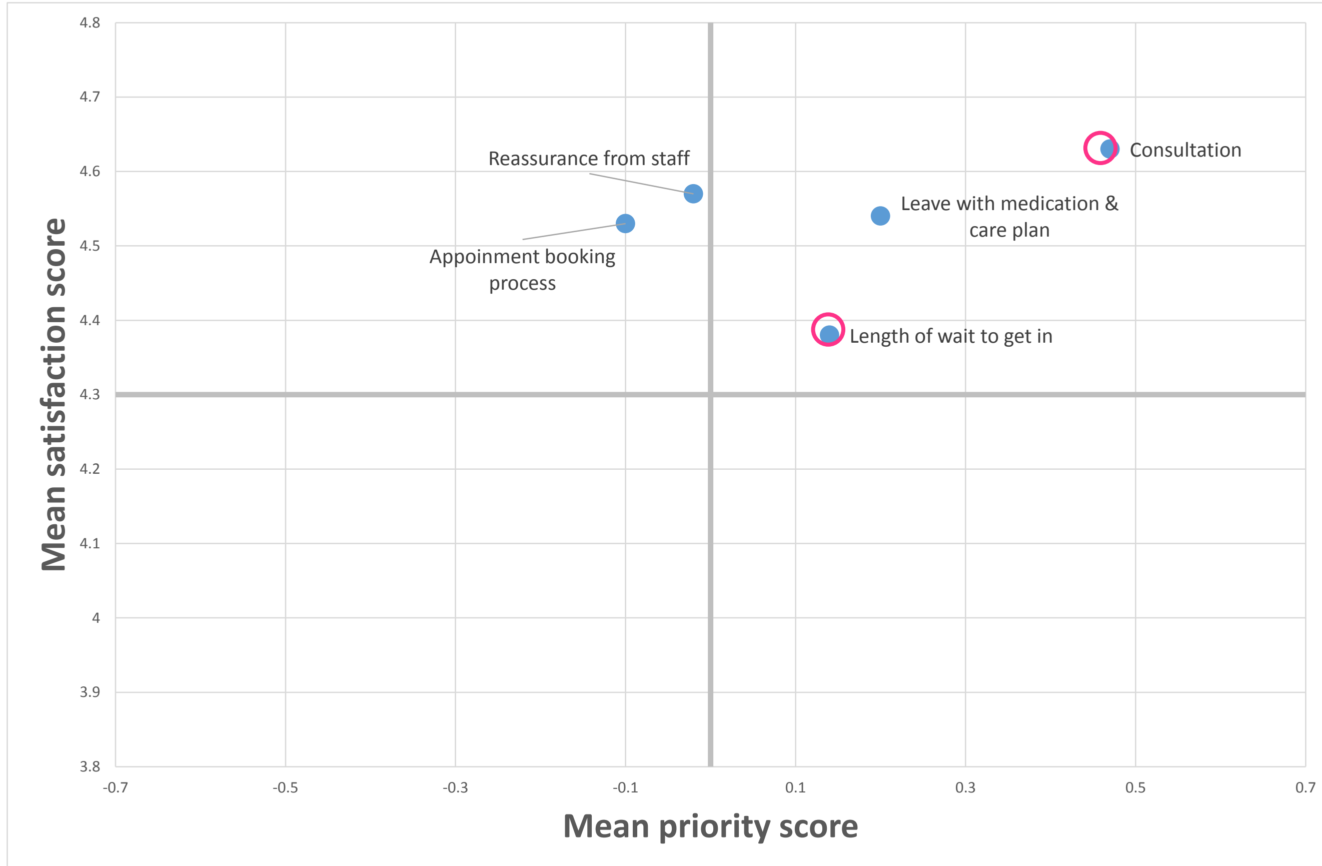
Lowest level of satisfaction for hospital discharge

Q35 Thinking about your experience, how satisfied were you with each of the following?

Q36 Thinking about the overall experience, how satisfied were you with the service you received?

NEMS

PRIORITY MAP



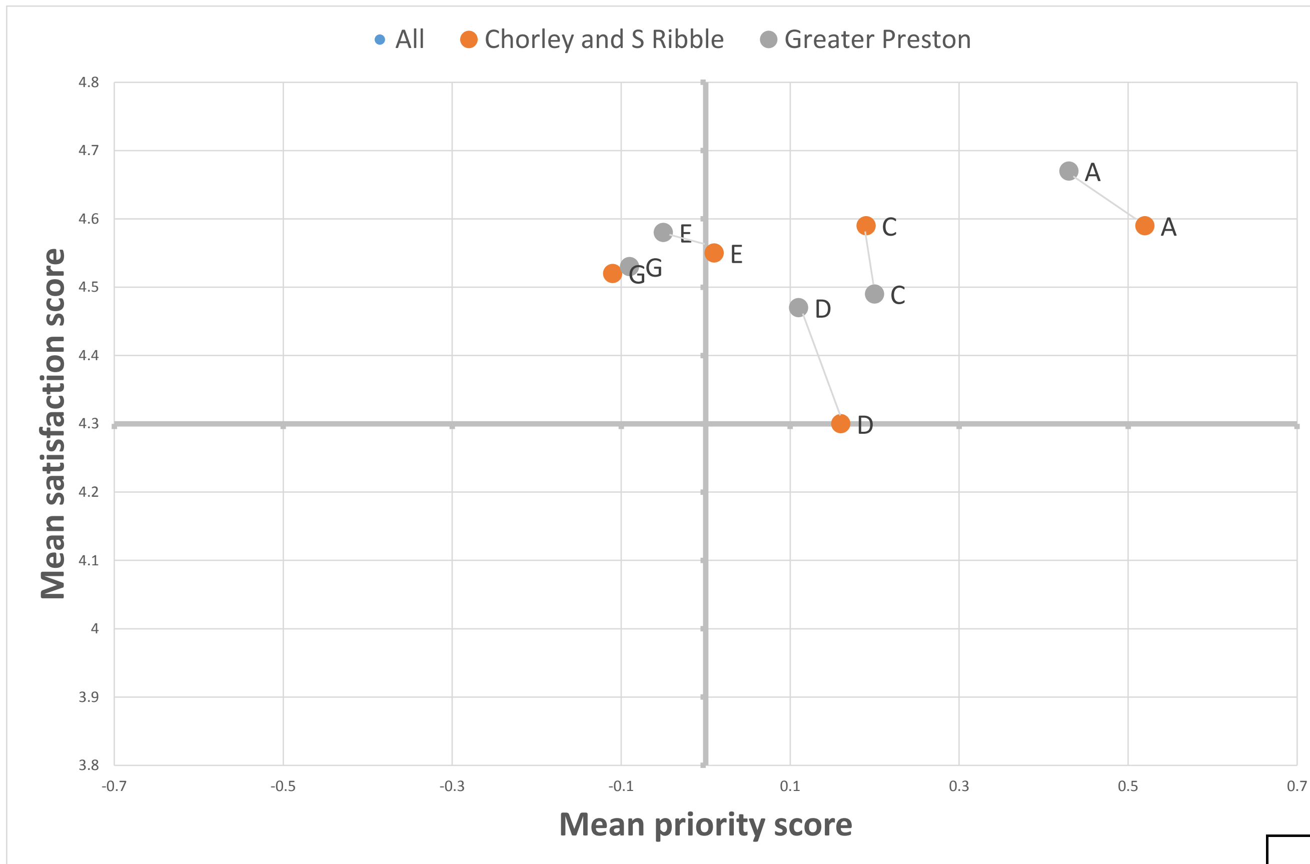
REVIEW | PROTECT
MONITOR | IMPROVE

High satisfaction levels for planned hospital visits means attributes are more about maintenance

Key priority segments, plus:
Dignity
Patient choice

Comparison of mean satisfaction score against mean priority score

PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

Satisfaction with 'length of wait' notably lower among Chorley & S Ribble residents and worth particular attention

A	Consultation
C	Leave with medication & care plan
D	Length of wait to get in
E	Reassurance from staff
G	Appoinment booking process

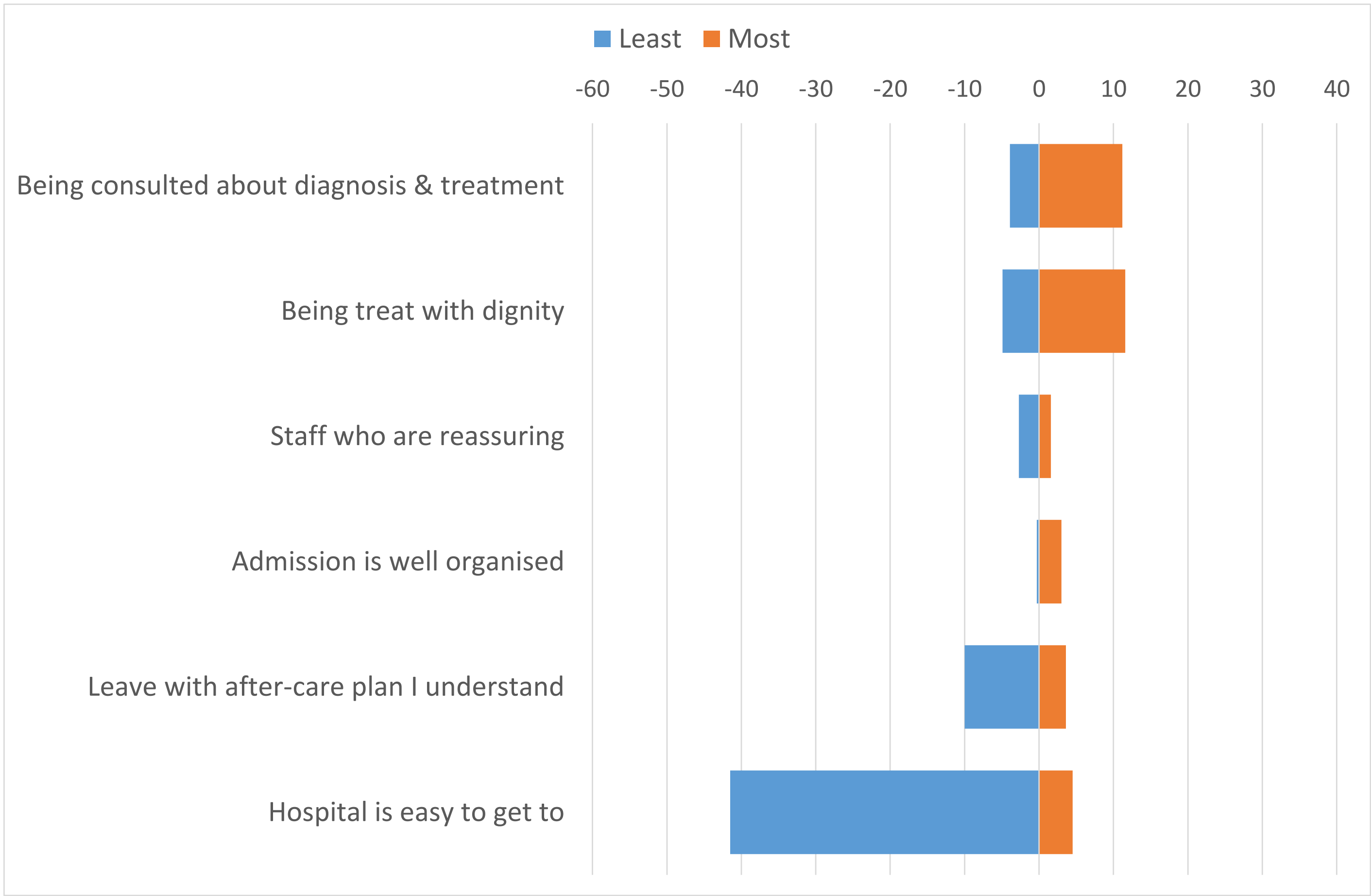
Comparison of mean satisfaction score against mean priority score

3.5

SERVICE PRIORITIES: **HOSPITAL (EMERGENCY)**

SUBSAMPLE: 300 RESPONDENTS

HOSPITAL EMERGENCY PRIORITIES

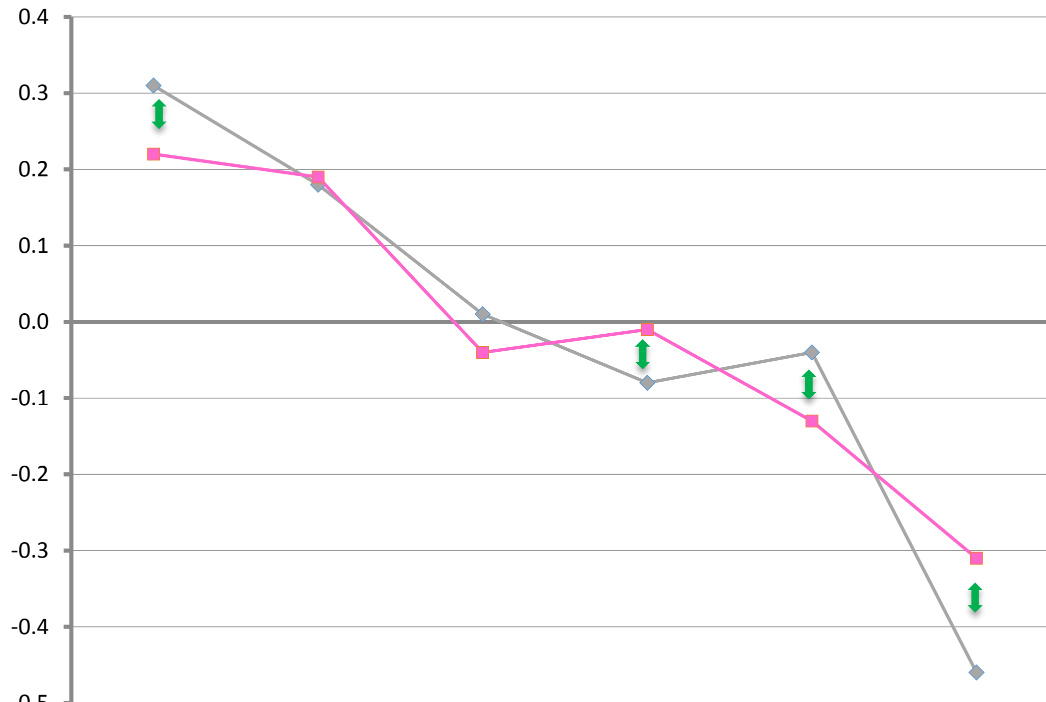


'Consulted about diagnosis and treatment' and 'treat with dignity' both show high priority, but opinion is clearly divided

Q51 Priority ranking of service attributes

Attribute ranking as percentage most and least important

HOSPITAL EMERGENCY PRIORITIES



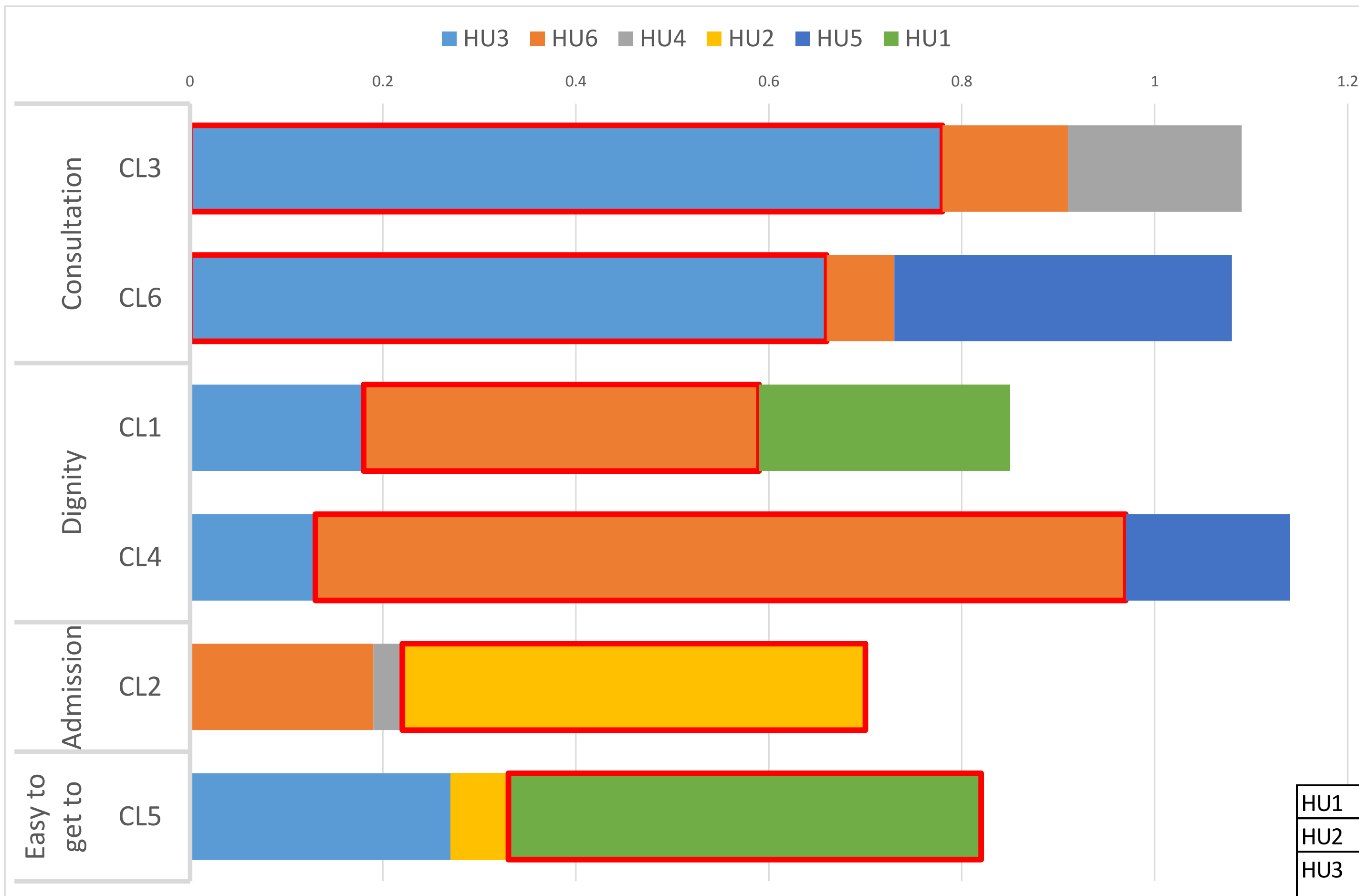
Priority mix broadly similar for the populations in the two CCG areas, but some notable differences on four of the six attributes

A	Being consulted about diagnosis & treatment
B	Being treat with dignity
C	Staff who are reassuring
D	Admission is well organised
E	Leave with after-care plan I understand
F	Hospital is easy to get to

Q51 Priority ranking of service attributes

Mean attribute ranking

'PRIORITY' SEGMENTS (top 3 priorities)

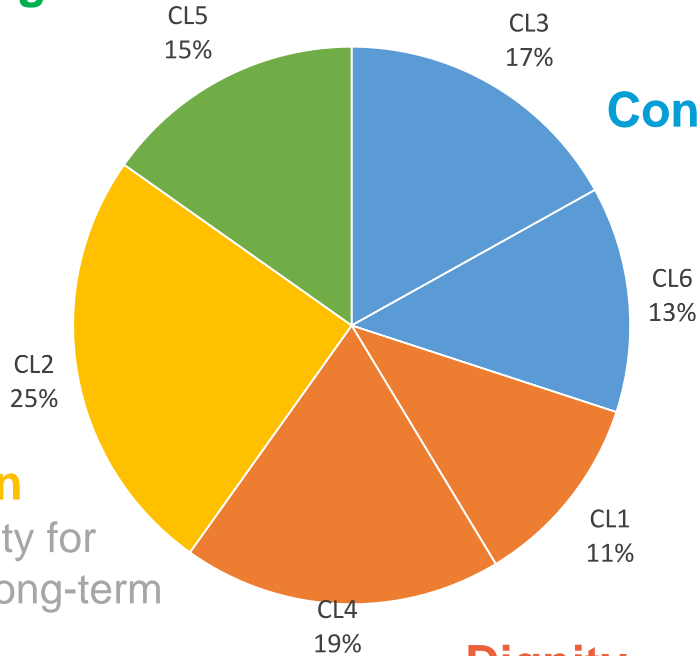


Overall sample priorities hide diversity of opinion

Groups in the population with clearly different priorities

HU1	Hospital is easy to get to
HU2	Admission is well organised
HU3	Being consulted about my diagnosis and treatment
HU4	Staff who are reassuring
HU5	Leaving with an after-care plan I understand
HU6	Being treat with dignity

HOSPITAL EMERGENCY: 'PRIORITY' SEGMENTS



Admission
Lower priority for those with long-term conditions

Dignity
Priority higher among women

Relative sizes of the different priority segments and any notable demographic differences

'Easy to get to' appears as a key priority group not evident for planned admissions

Clearly different mix for the two CCGs

	CSR	GP
Consultation	34%	27%
Dignity	40%	22%
Admission	14%	33%
Easy to get to	12%	17%

IMPACT OF ADMISSION WAIT ON SATISFACTION

Percentage very satisfied with organisation of admission:

Wait on admission	Percentage very satisfied
No wait	71%
Up to 30 mins	52%
Up to 1 hr	48%
2 hrs	43%
3 hrs	7%
4 hrs	0%
5 hrs	0%

Wait longer than 2 hours:
Chorley & S Ribble hospital = 10% of respondents
Greater Preston hospital = 24% of respondents

Clear 'trigger' point for over 2 hours

Q25 How long did you have to wait on admission?

Q27 Thinking about your experience, how satisfied were you with each of the following? *Organisation of my admission*

EPISODE SATISFACTION

	Quite dissatisfied	Very dissatisfied	Very satisfied	Quite satisfied
Organisation of my admission	-8	-1	55	26
Consultation with medical staff about my diagnosis and treatment	-4	-8	56	19
Reassurance from staff	-7	-4	51	24
Confident in my diagnosis and treatment	-3	-5	61	19
My discharge was well planned	-8	-7	59	19
I left with all the medication and understanding of my care plan I needed for when I got home	-1	-7	68	17
OVERALL EPISODE	-3	-6	53	26

Affected by actual wait on admission: Increase in impact at approx. 2 hours

As with planned hospital visits, discharge records moderate levels of dissatisfaction

Q27 Thinking about your experience, how satisfied were you with each of the following?

Q28 Thinking about the overall experience, how satisfied were you with the service you received?

NEMS

PRIORITY MAP

REVIEW | PROTECT
MONITOR | IMPROVE

Consultation with patients about diagnosis and treatment; one of the key attributes to effect satisfaction improvement

Key priority segments, plus:
Dignity
Easy to get to

Comparison of mean satisfaction score against mean priority score

PRIORITY MAP

All
Chorley and S Ribble
Greater Preston

Mean satisfaction score

4.8
4.7
4.6
4.5
4.4
4.3
4.2
4.1
4
3.9
3.8

E E
D D
C
A
C A

-0.7 -0.5 -0.3 -0.1 0.1 0.3 0.5 0.7

Mean priority score

REVIEW	PROTECT
MONITOR	IMPROVE

Chorley and S Ribble residents less satisfied with both ‘consultation about diagnosis & treatment’ and ‘reassurance from staff’

A	Consultation
C	Reassurance from staff
D	Organisation of admission
E	Left with medication and understanding of care plan

Comparison of mean satisfaction score against mean priority score

3.6

SERVICE PRIORITIES: **COMMUNITY CARE**

SUBSAMPLE: 298 RESPONDENTS

Approximately equal split between self and third party; Of third party experience, 57% were for parents experiencing community care.

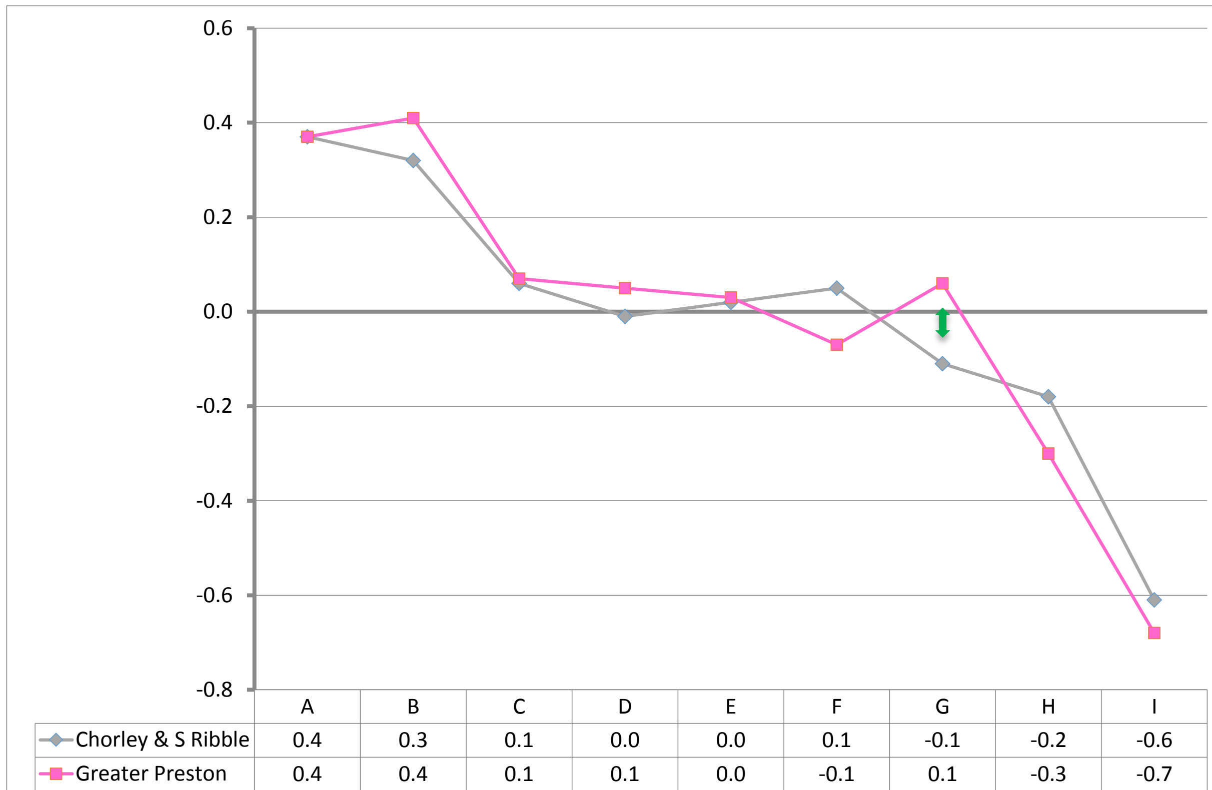
COMMUNITY CARE PRIORITIES

Some attributes with a lower mean priority score, are most important for significant numbers of patients

Q51 Priority ranking of service attributes

Attribute ranking as percentage most and least important

COMMUNITY CARE PRIORITIES



	A	B	C	D	E	F	G	H	I
Chorley & S Ribble	0.4	0.3	0.1	0.0	0.0	0.1	-0.1	-0.2	-0.6
Greater Preston	0.4	0.4	0.1	0.1	0.0	-0.1	0.1	-0.3	-0.7

Priority mix broadly similar for the populations in the two CCG areas

'Help to do things myself' notably higher in Greater Preston

A	Being consulted about treatment
B	Being treat with dignity
C	Seeing same staff each time
D	Staff who are reassuring
E	Visits not being rushed
F	Well organised appointment times
G	Help to do things myself
H	Able to choose from alternative services
I	Ease or help getting there

Q51 Priority ranking of service attributes

Mean attribute ranking

'PRIORITY' SEGMENTS (top 3 priorities)

CC4 CC9 CC7 CC5 CC6 CC8 CC3 CC1 CC2

0 0.2 0.4 0.6 0.8 1 1.2 1.4 1.6 1.8

Dignity: CL2, CL7, CL1

Support: CL4

Same staff: CL3, CL6

Length of visit: CL8

Appointments: CL5

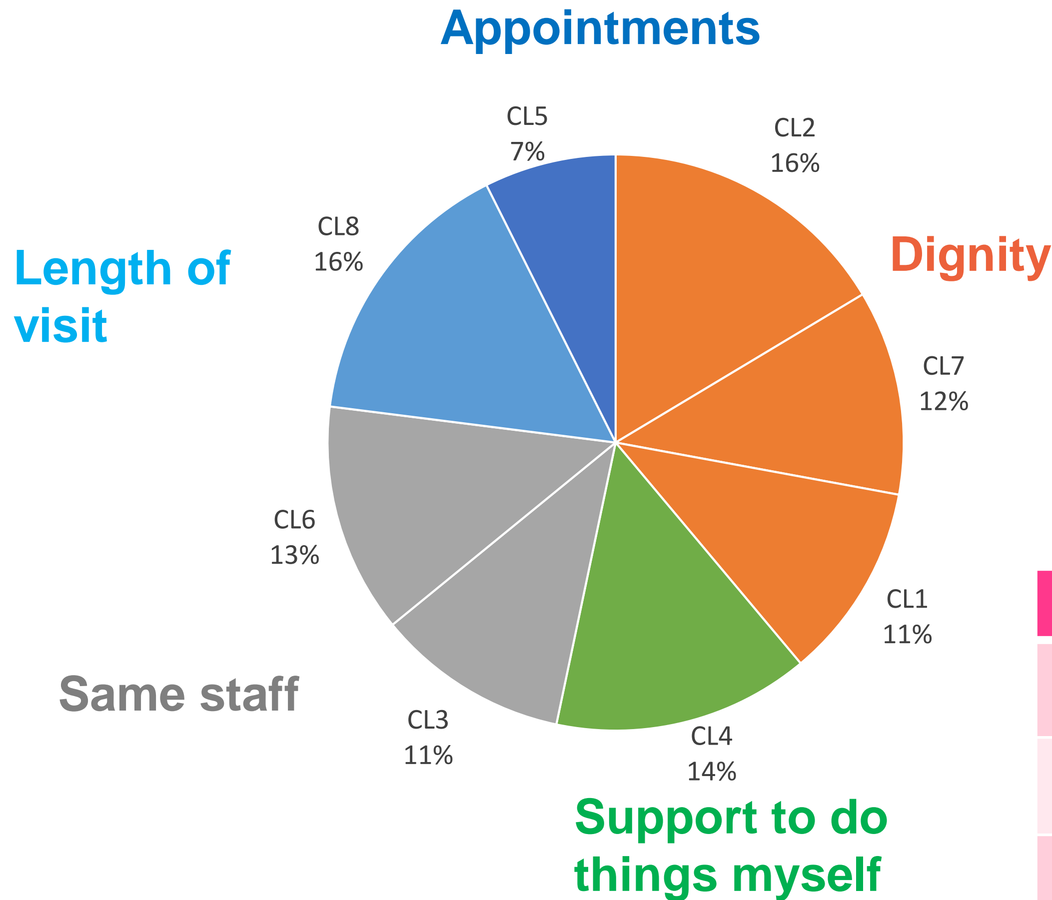
Overall sample priorities hide diversity of opinion

Groups in the population with clearly different priorities

CC1	Being able to choose from alternative services
CC2	Ease or help getting there
CC3	Well organised appointment times
CC4	Being consulted about my treatment
CC5	Staff who are reassuring
CC6	Visits not being rushed
CC7	Seeing the same staff each time
CC8	Help to do things myself in everyday life to improve my condition
CC9	Being treat with dignity

NEMS

COMMUNITY CARE: 'PRIORITY' SEGMENTS

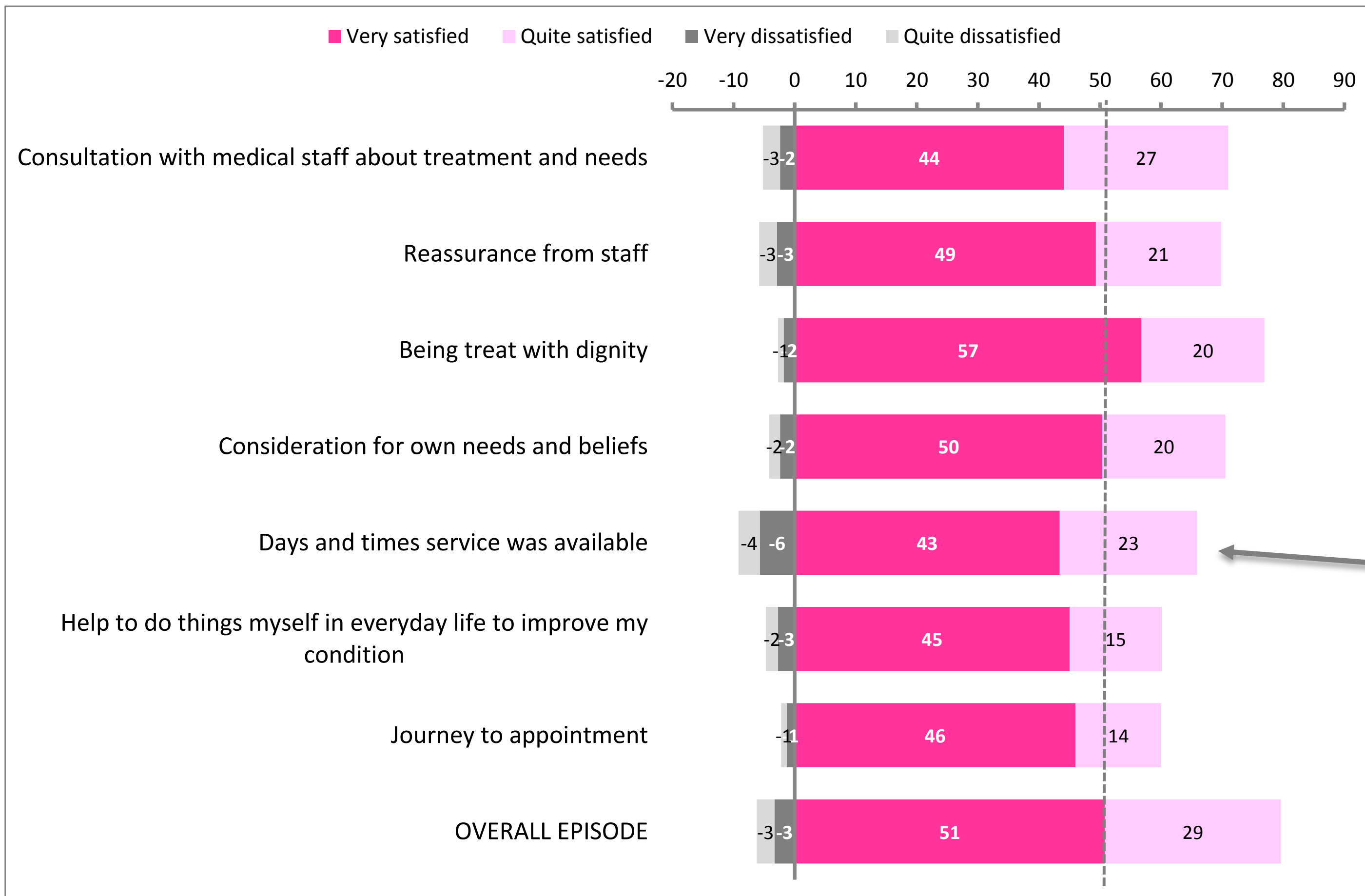


Relative sizes of the different priority segments and any notable demographic differences

Differing mix for the two CCG areas

	CSR	GP
Dignity	49%	30%
Same staff	23%	24%
Length of visit	12%	19%
Support to do things myself	11%	17%
Appointments	5%	9%

EPISODE SATISFACTION



Community care scored lowest on episode satisfaction of the four services measured

It's high episode frequency will impact heavily on overall NHS service satisfaction

Lowest attribute satisfaction for 'days and times service was available'

Q48 Thinking about your experience, how satisfied were you with each of the following?

Q49 Thinking about the overall experience, how satisfied were you with the service you received?

PRIORITY MAP

Mean satisfaction score

4.8
4.7
4.6
4.5
4.4
4.3
4.2
4.1
4
3.9
3.8

Treat with dignity

Journey to appointment

Help to do things myself

Consultation

Reassurance from staff

-0.7 -0.5 -0.3 -0.1 0.1 0.3 0.5 0.7

Mean priority score

REVIEW | PROTECT

MONITOR | IMPROVE

Key attribute ‘dignity’ has relatively high satisfaction

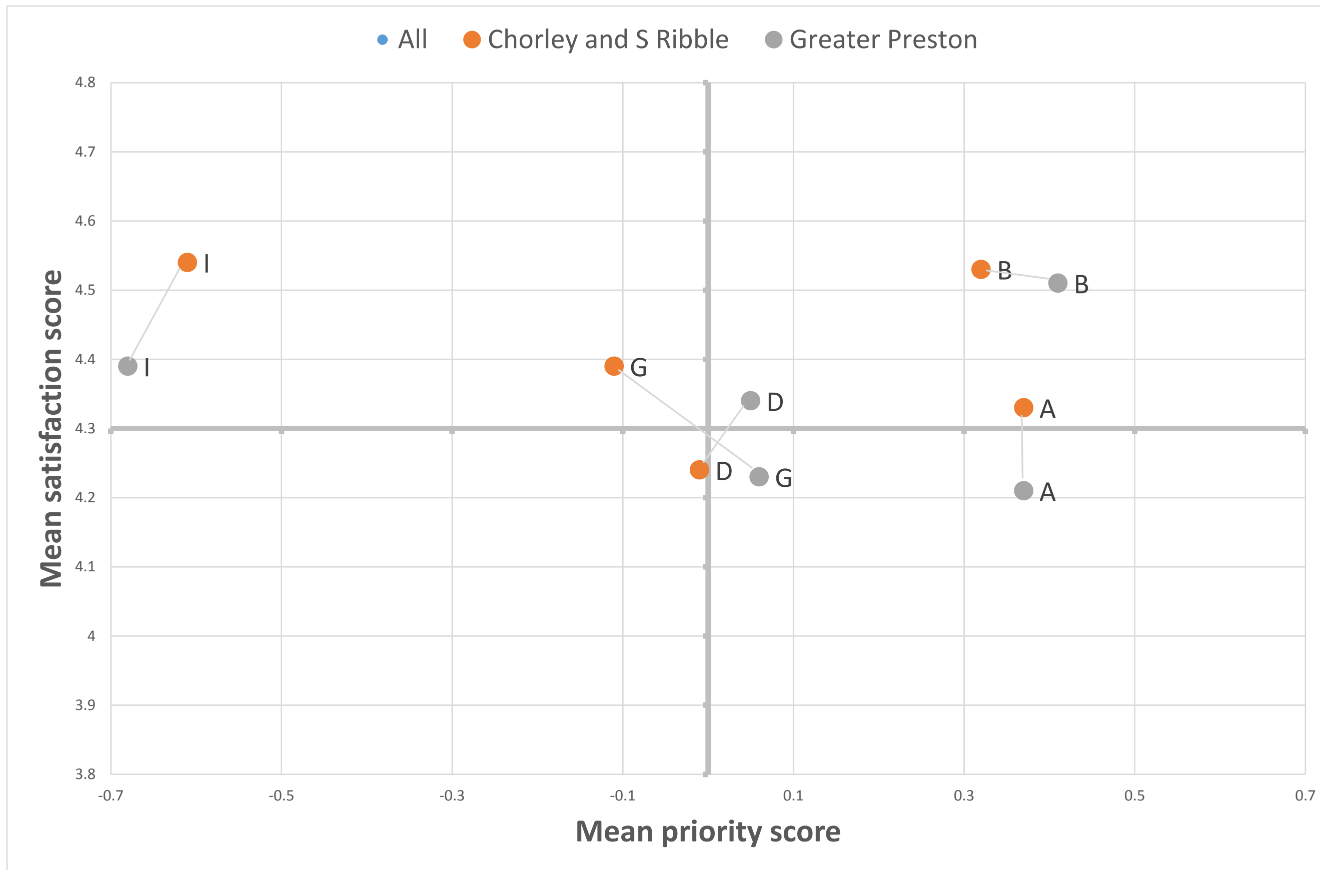
While ‘reassurance’ and ‘consultation’ are clearly lower scoring high priority attributes, other technical attributes such as seeing same staff, length of visit and organisation of appointments are key

Key priority segments, plus:
Seeing the same staff
Length of visit
Organised appointments

Comparison of mean satisfaction score against mean priority score

NEMS

PRIORITY MAP



REVIEW	PROTECT
MONITOR	IMPROVE

‘Consultation’ and ‘help to do things myself’ notably scoring lower on satisfaction in Greater Preston

A	Consultation
B	Treat with dignity
D	Reassurance from staff
G	Help to do things myself
I	Journey to appointment

Comparison of mean satisfaction score against mean priority score

6.7

SERVICE PRIORITIES: GP

SUBSAMPLE: 879 RESPONDENTS

GP PRIORITIES

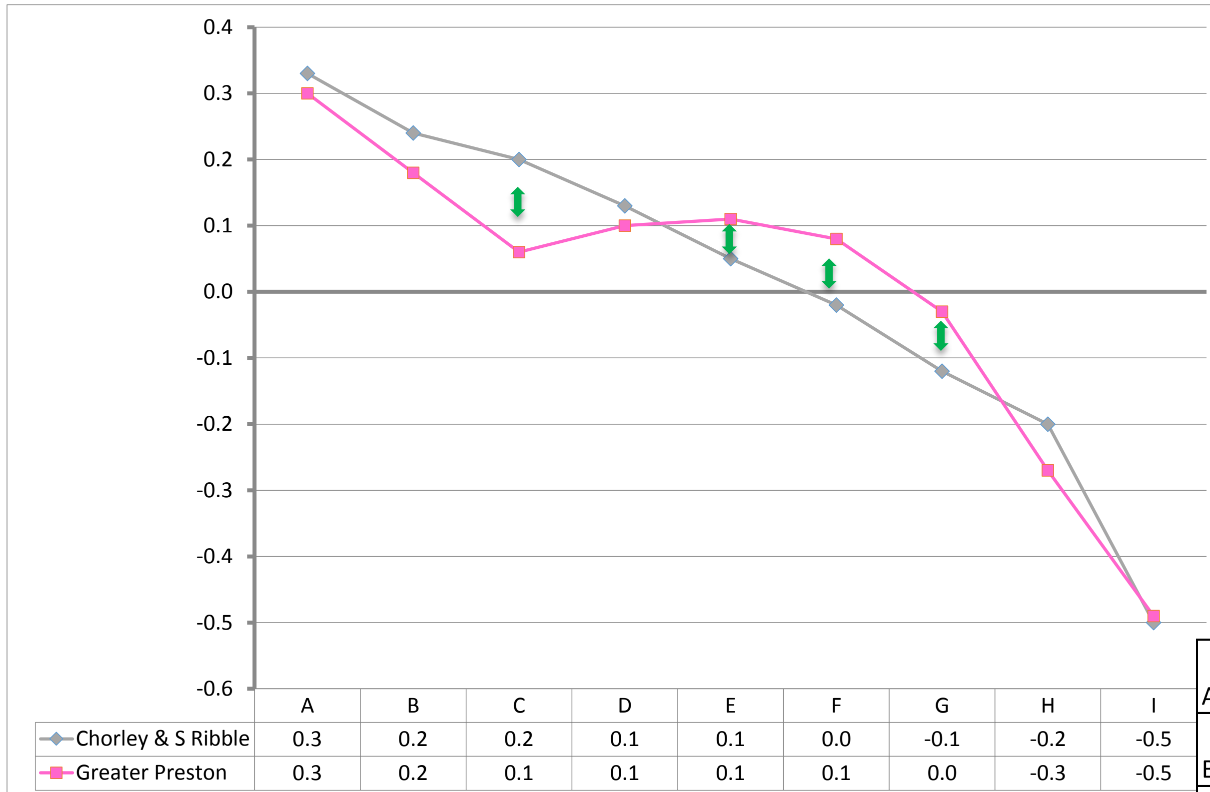
'Consultation' generally a high priority for patients

But 'seeing the same doctor' and service availability more extreme with polarised views

Q51 Priority ranking of service attributes

Attribute ranking as percentage most and least important

GP PRIORITIES



	A	B	C	D	E	F	G	H	I
Chorley & S Ribble	0.3	0.2	0.2	0.1	0.1	0.0	-0.1	-0.2	-0.5
Greater Preston	0.3	0.2	0.1	0.1	0.1	0.1	0.0	-0.3	-0.5

Priority mix broadly similar for the populations in the two CCG areas

‘Seeing same doctor’ notably lower priority in Greater Preston

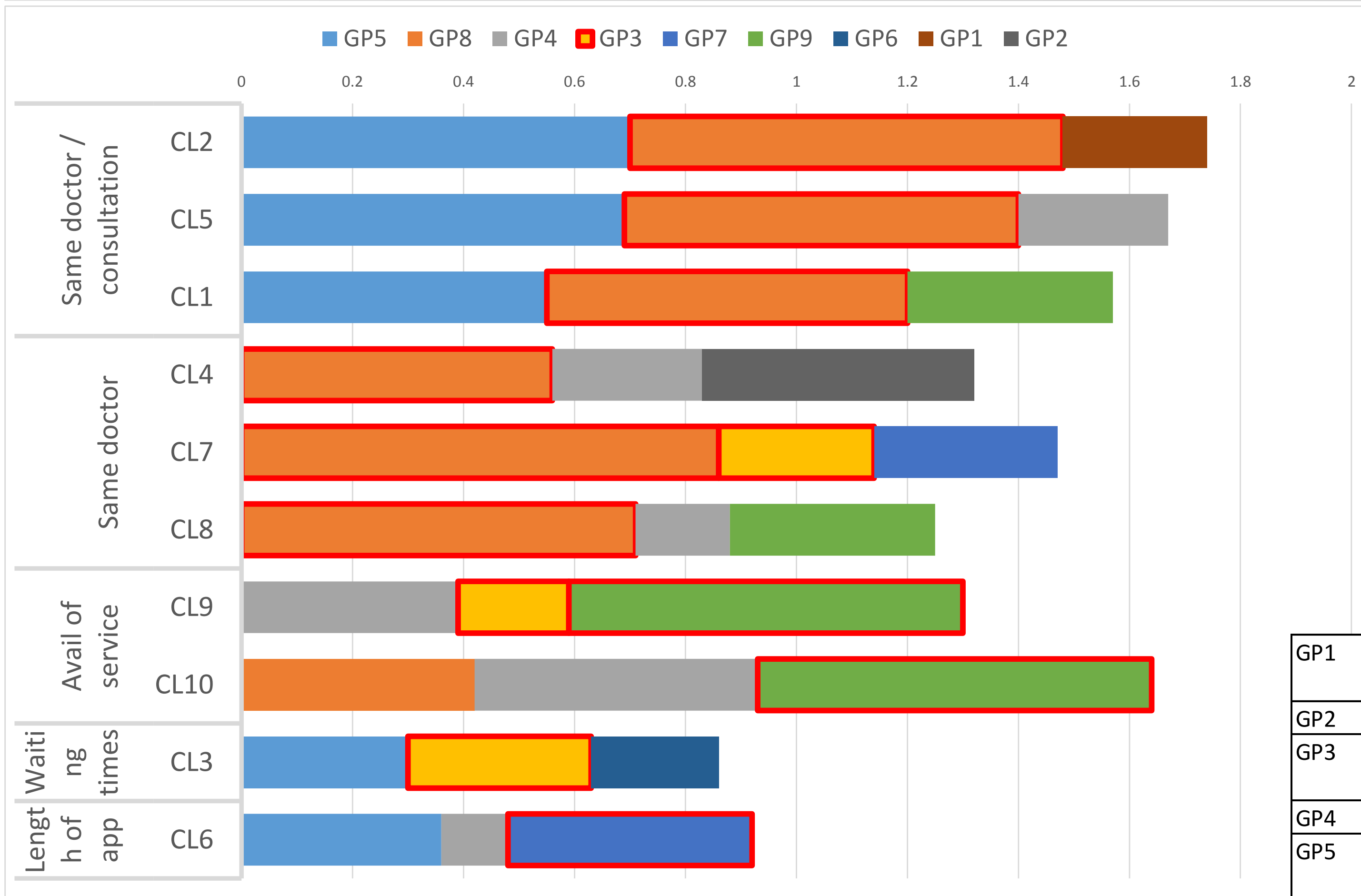
‘Waiting times’, ‘appointment being rushed’ and ‘reassurance’ notably higher in CSR

A	Being consulted about diagnosis & treatment
B	Easy appointment booking
C	Seeing same doctor each time
D	Service avail on evenings & weekends
E	Short waiting time for appointment
F	Appointment not being rushed
G	Staff who are reassuring
H	Able to choose from alternative services
I	Easy to get to

Q51 Priority ranking of service attributes

Mean attribute ranking

‘PRIORITY’ SEGMENTS (top 3 priorities)



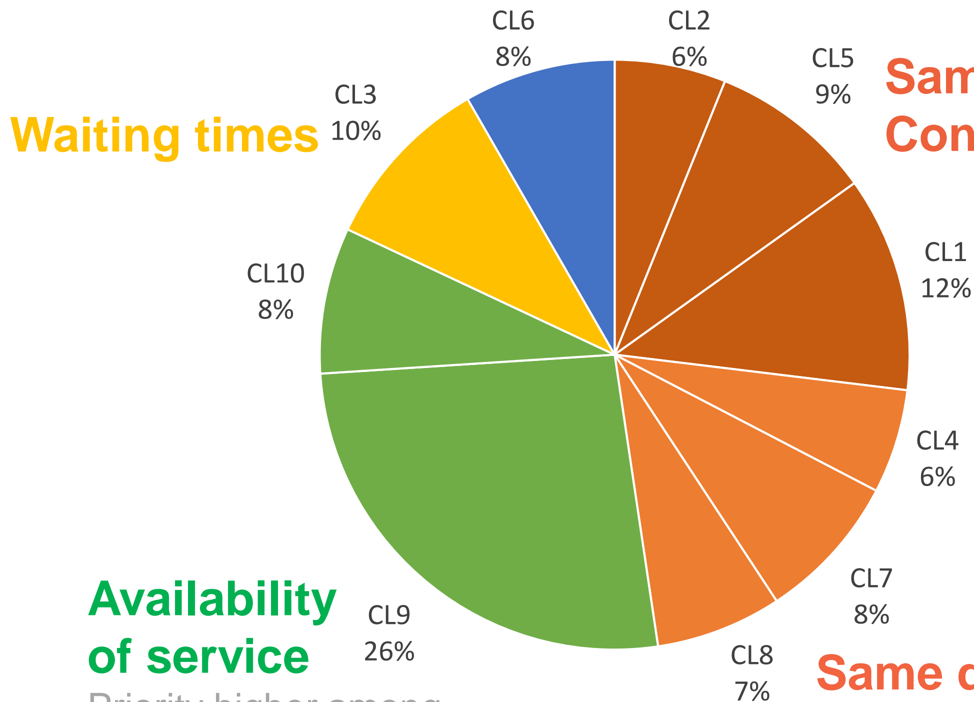
Overall sample priorities hide diversity of opinion

Groups in the population with clearly different priorities

Influence of ‘seeing the same doctor each time’ clearly evident

GP1	Being able to choose from alternative services
GP2	GP surgery is easy to get to
GP3	Short waiting time for appointment
GP4	Easy appointment booking
GP5	Being consulted about my diagnosis and treatment
GP6	Staff who are reassuring
GP7	Appointment not being rushed
GP8	Seeing the same doctor each time
GP9	Service availability on evenings and weekends

GP: ‘PRIORITY’ SEGMENTS



Same doctor > Consultation

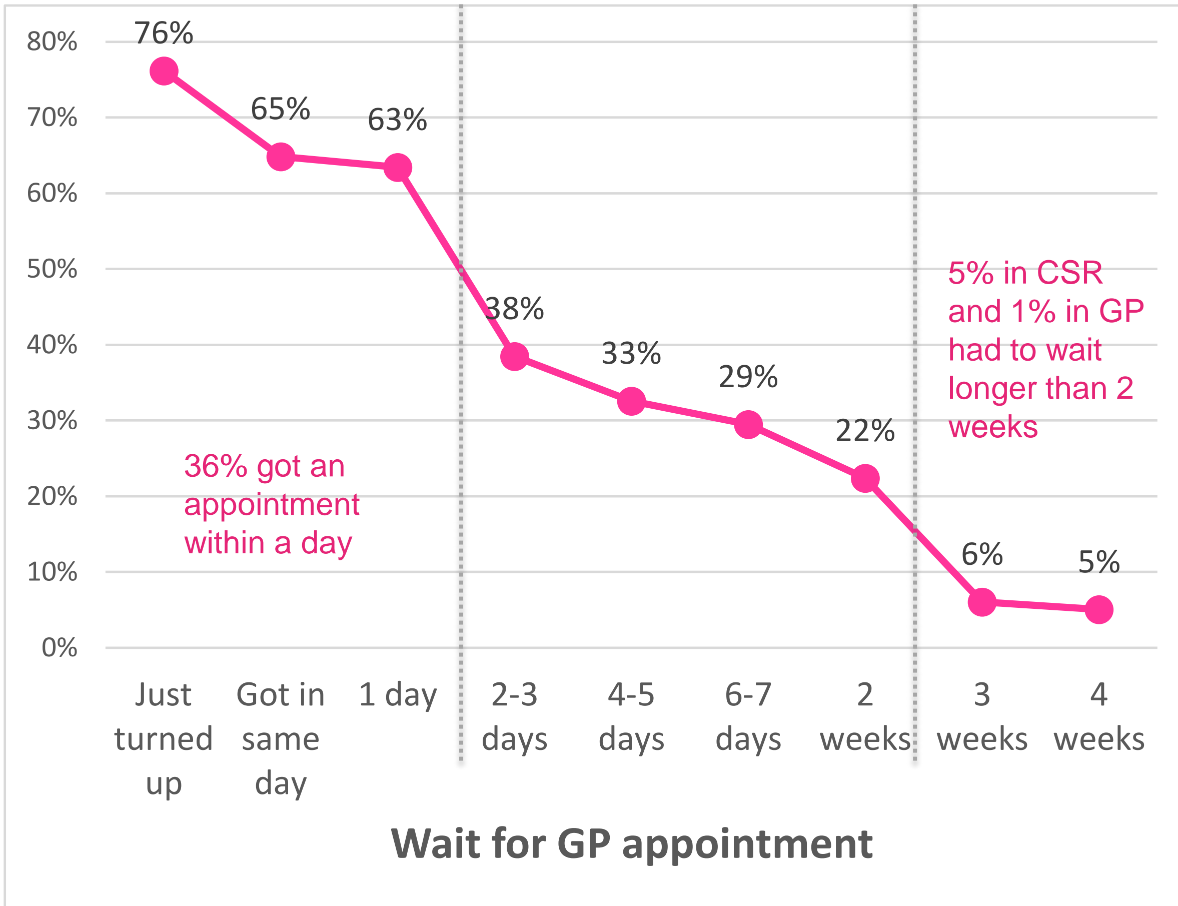
Priority higher among those aged 55 and over, and those with long-term conditions

Priority higher among ABC1s

	CSR	GP
Same doctor >Consultation	28%	26%
Same doctor	23%	19%
Availability of service	34%	32%
Waiting times	6%	13%
Length of appointment	8%	9%

IMPACT OF WAITING TIMES ON SATISFACTION

Percentage very satisfied with length of wait to get appointment:



Two clear 'trigger' points for large fall in satisfaction:

> 1 day

> 2 weeks

Q39 How long did you have to wait for an appointment?

Q42 Thinking about your experience, how satisfied were you with each of the following? *Length of wait to get an appointment*

NEMS

EPISODE SATISFACTION

	Quite dissatisfied	Very dissatisfied	Very satisfied	Quite satisfied
Length of wait to get an appointment	-5	-9	44	25
Days and times service was available for my appointment	-6	-7	45	30
Consultation with me about my diagnosis and treatment	-2	-3	56	25
Reassurance from doctor/nurse	-2	-3	62	23
Confident in my diagnosis and treatment	-3	-4	61	22
OVERALL EPISODE	-3	-4	60	22

Directly affected by actual wait for appointment

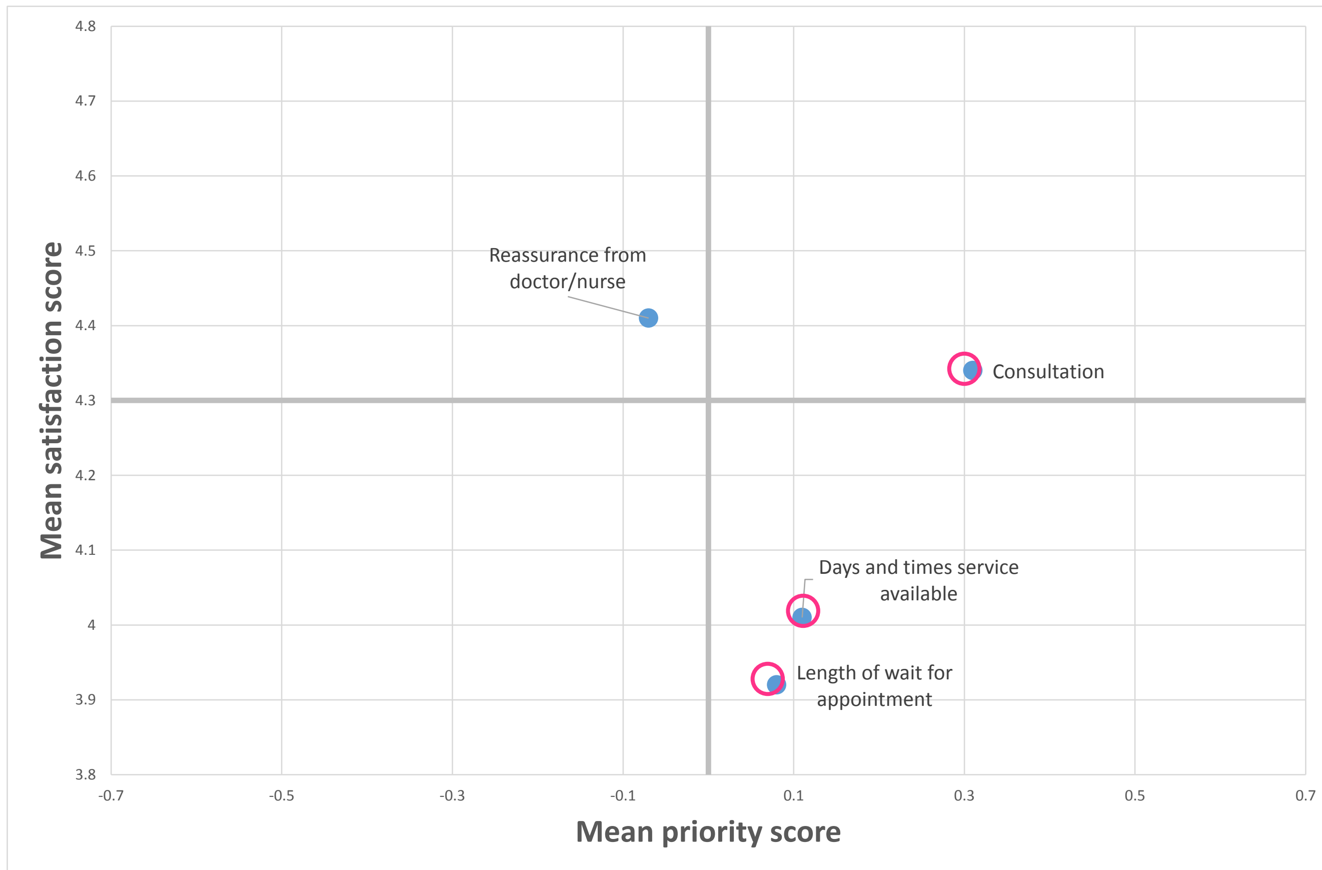
Technical attributes of 'length of wait to get an appointment' and 'days and times service available' scored notably lower attribute satisfaction

Q42 Thinking about your experience, how satisfied were you with each of the following?

Q43 Thinking about the overall experience, how satisfied were you with the service you received?

NEMS

PRIORITY MAP



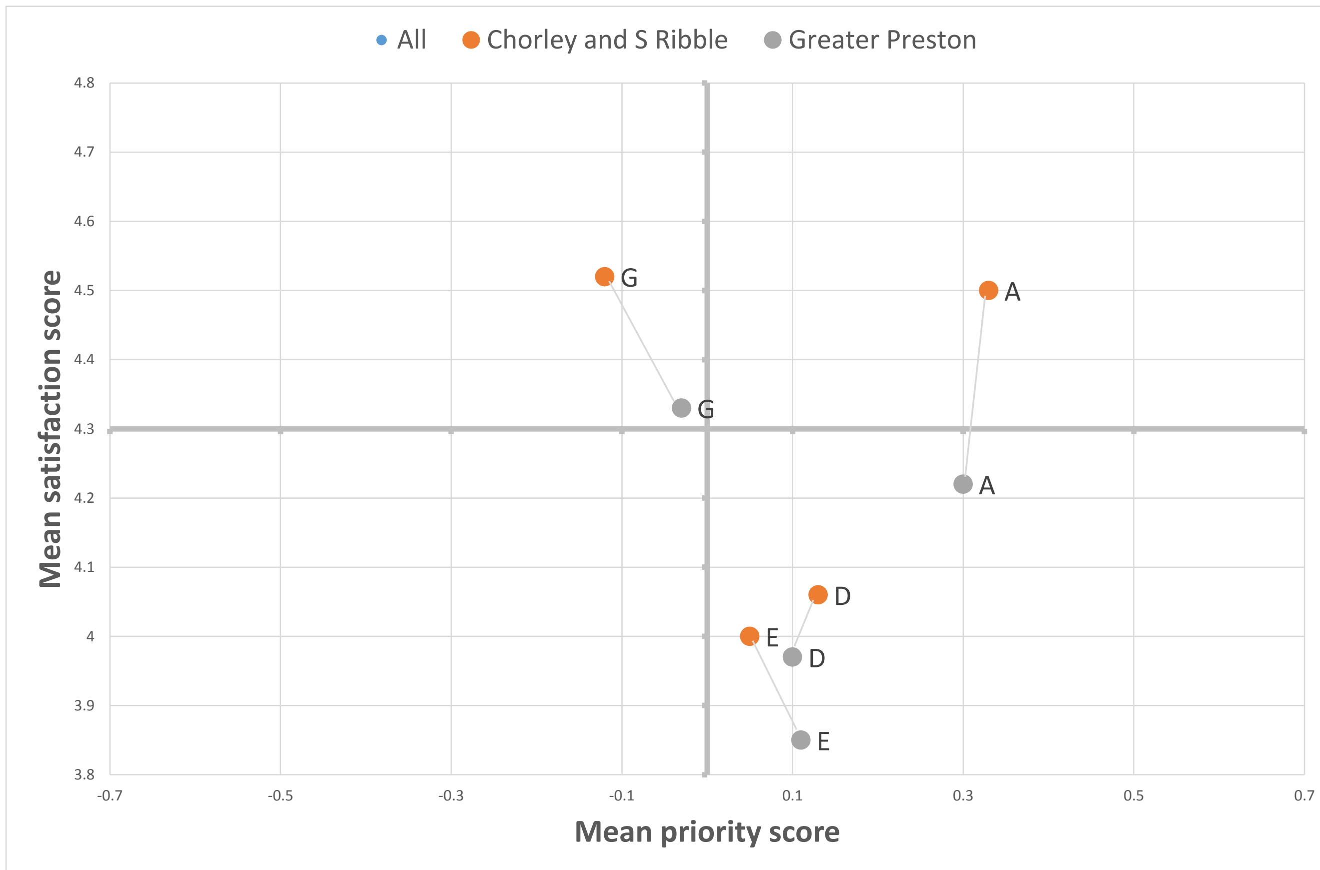
REVIEW | PROTECT
MONITOR | IMPROVE

Critical nature of service availability and waiting times self-evident

Key priority segments, plus:
Seeing same doctor
Length of appointment

Comparison of mean satisfaction score against mean priority score

PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

Satisfaction with GP services lower in Greater Preston

A	Consultation
D	Days and times service available
E	Length of wait for appointment
G	Reassurance from doctor/nurse

Comparison of mean satisfaction score against mean priority score

NEMS

8.

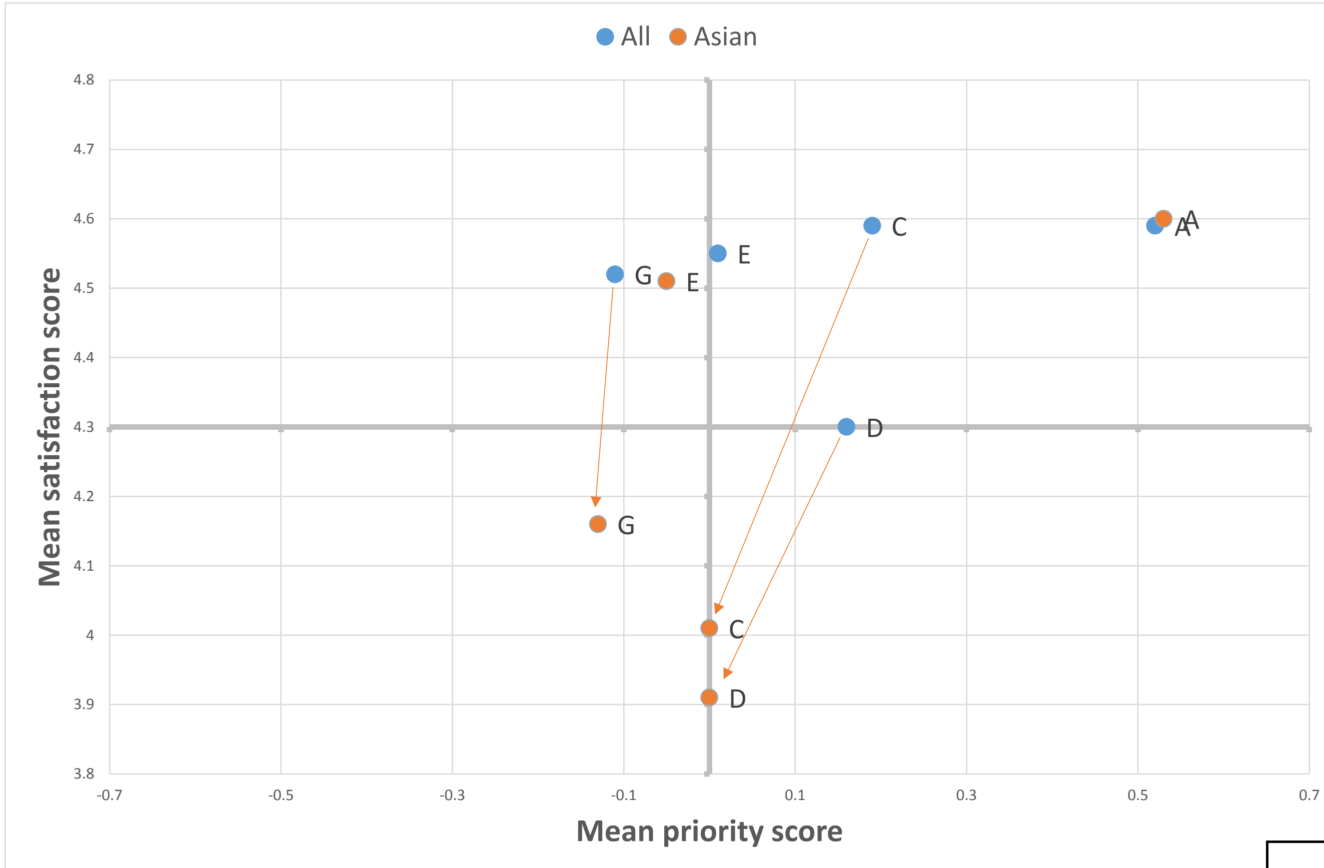
SERVICE PRIORITIES **BME/ASIAN**

SUBSAMPLE: 200 RESPONDENTS

ASIAN POPULATION: KEY DIFFERENCES

- Lifestyle and conditions
  - Less likely to smoke and much less likely to drink alcohol
  - Lower prevalence of depression/anxiety
  - Higher prevalence of diabetes
- Less likely to give extremity of response (very satisfied or dissatisfied) to any of the satisfaction ratings
- Lower overall rating of services
- Satisfaction with hospital services lower:
  - As high if not higher on emotional attributes
  - Notably lower satisfaction on technical issues, e.g. booking, admission and discharge
- Satisfaction with community care services lower:
  - Lower on technical attributes; service availability, and journey to appointment
  - Lower on emotional issues; consideration for own needs and beliefs, and ‘help to do things myself’
- Service priority rankings ….

HOSPITAL PLANNED: PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

Lower satisfaction among Asian community for:

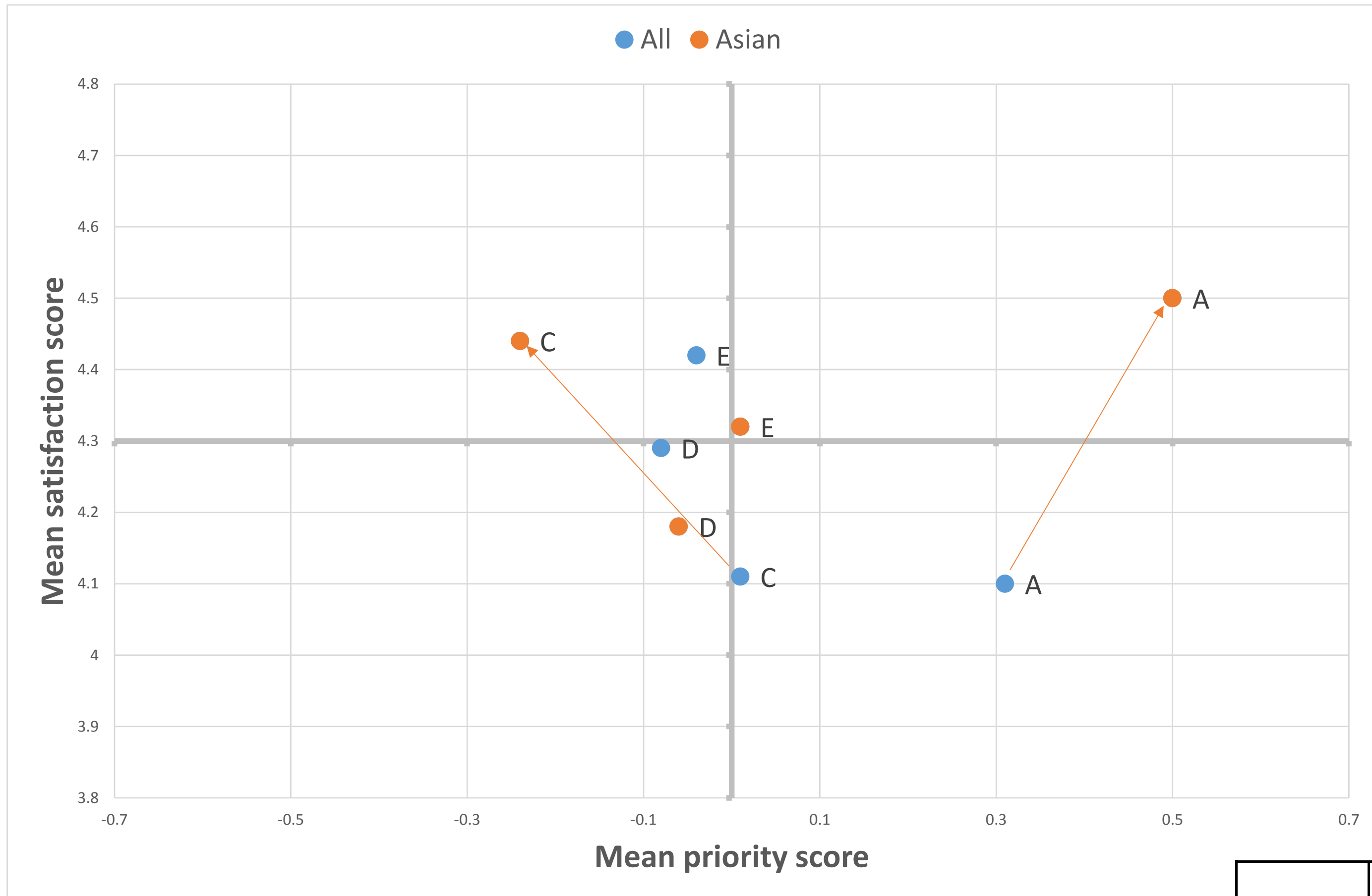
Leaving care plan;
Wait to get in;
Booking process

Comparison of mean satisfaction score against mean priority score

A	Consultation
C	Leave with medication & care plan
D	Length of wait to get in
E	Reassurance from staff
G	Appoinment booking process

NEMS

HOSPITAL EMERGENCY: PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

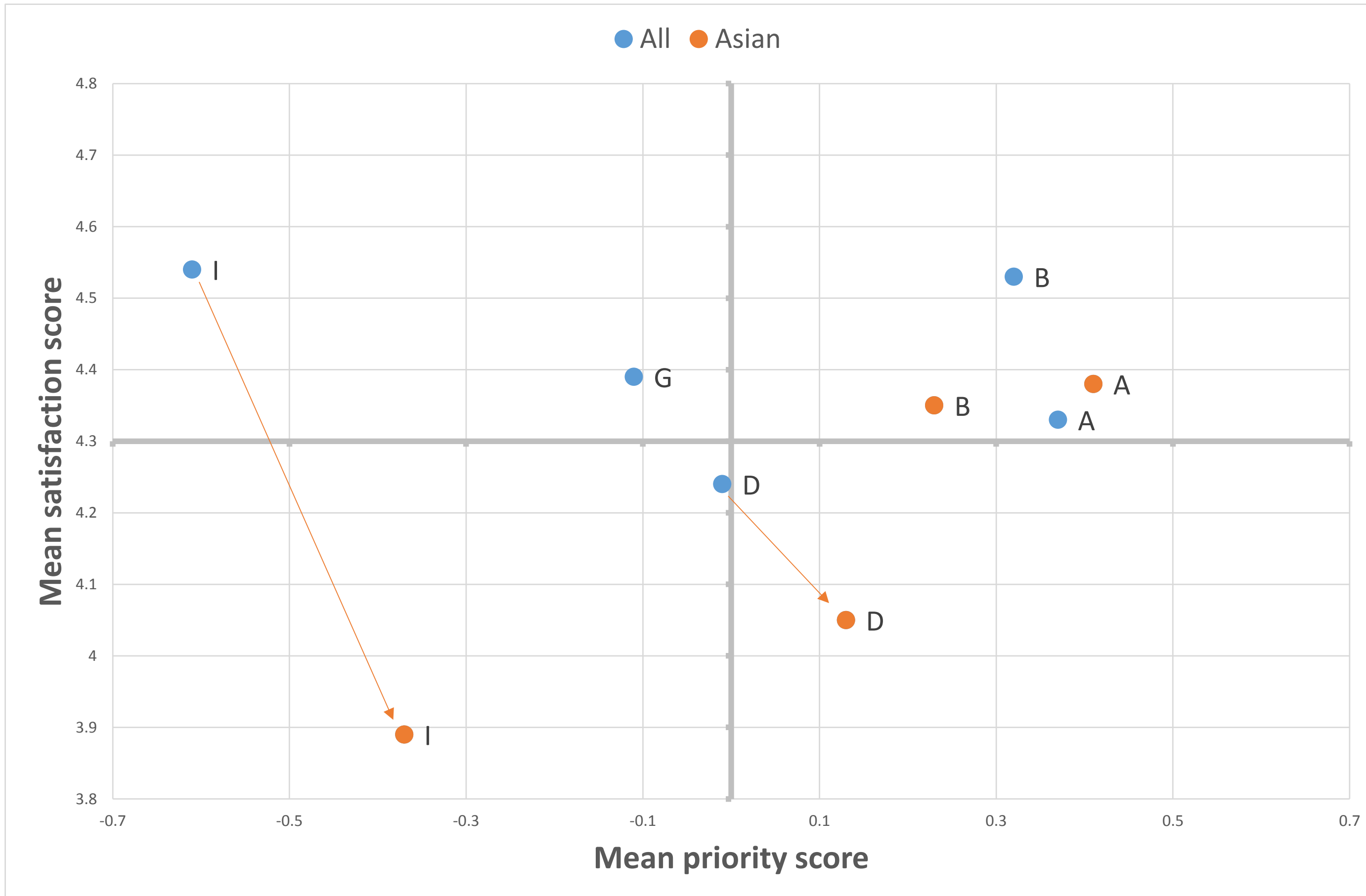
Higher satisfaction among Asian community with emotional attributes (‘consultation’ and ‘reassurance’)

Lower satisfaction for ‘organisation of admission’

Comparison of mean satisfaction score against mean priority score

A	Consultation
C	Reassurance from staff
D	Organisation of admission
E	Left with medication and understanding of care plan

COMMUNITY CARE: PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

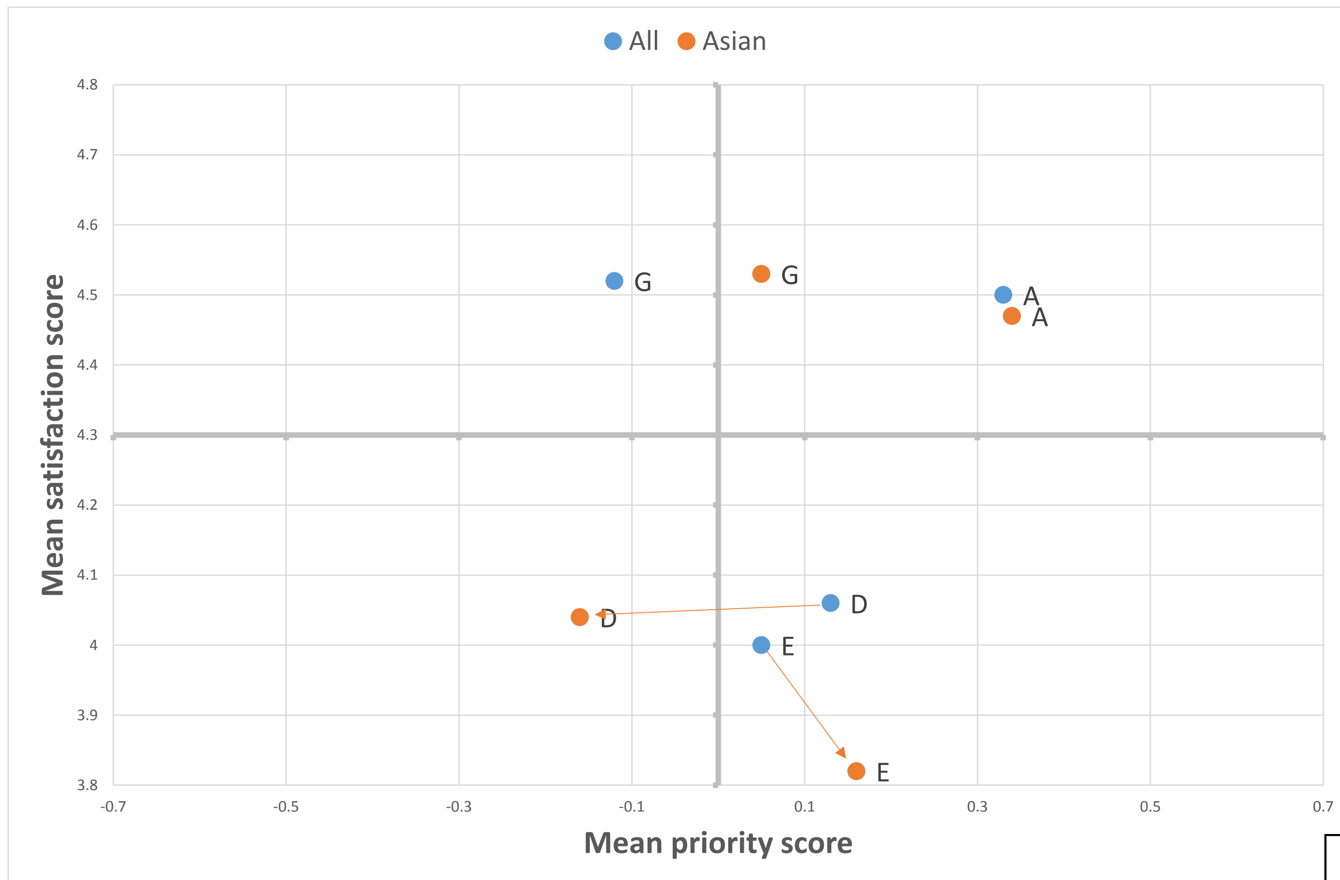
Higher priority and lower satisfaction among Asian community for:

Reassurance from staff;
Journey to appointment

A	Consultation
B	Treat with dignity
D	Reassurance from staff
G	Help to do things myself
I	Journey to appointment

Comparison of mean satisfaction score against mean priority score

GP/DOCTOR: PRIORITY MAP



REVIEW | PROTECT
MONITOR | IMPROVE

Asian community:

Higher priority and lower satisfaction for 'length of wait for appointment';

Lower priority for 'days and times service available

A	Consultation
D	Days and times service available
E	Length of wait for appointment
G	Reassurance from doctor/nurse

Comparison of mean satisfaction score against mean priority score

9.

SERVICE PRIORITIES
KEY CONCLUSIONS

SERVICES: KEY CONCLUSIONS

- High levels of overall satisfaction
  - Demographic effect: men and older age groups rate satisfaction higher
- General satisfaction – cumulative experience of episodes
  - Episodes dominated by GP visits and community care
- Patient priorities – the lens through which satisfaction is viewed
  - A personality trait
  - Key priority groups (segments) - differing priority sets
  - Affects impact of attribute satisfaction on episode satisfaction
- Trigger points for service attributes
  - Hospital appointments: 2 months and 6 months
  - 2 hour wait for hospital emergency
  - GP appointments: 1 day and 2 weeks
- Classifying service attributes
  - By priority and satisfaction
  - Key attributes to address to potentially achieve maximum impact – high priority and low satisfaction

SUMMARY OF PRIORITIES FOR PLANNING

PURPLE: emotional attributes
BLACK: technical attributes
BLUE: Asian community (where differs)

	Hospital: Planned	Hospital: Emergency	Community Care	GP
IMPROVE: (higher priority and lower satisfaction)	Wait to get in; Leaving medication & care plan	Consultation about diagnosis and treatment	Consultation about treatment; Reassurance from staff	Length of wait for appointment; Days and times service available
MONITOR: (lower priority and lower satisfaction)	Appointment booking process	Reassurance from staff	Help to do things for themselves	
OTHER: (key priority segments)	Dignity; Patient choice	Dignity; Easy to get to	Seeing same staff; Length of visit; Organisation of appointments	

SUMMARY OF PRIORITY SEGMENTS ACROSS ALL 4 SERVICES

	Hospital – planned	Hospital – emergency	Community care	GP
Dignity	25	30 (36)	39	X
Seeing same staff/doctor	--	X	24	48 (67)
Consultation re diagnosis & treatment	42	30 (37)	--	27 (37)
Waiting time	23	X	X	10 (13)
Availability of service	X	X	X	34 (15)
Support to do things myself	X	X	14	X
Patient choice	10	X	--	--
Easy to get to	--	15 (16)	--	--
Organisation of admission	X	25 (11)	X	X

Numbers denote percentage of population in priority segment;
Numbers in brackets denote percentage of those with long-term conditions in segment, where notably different to population;
Grey shading denotes attribute was not measured in that service;
-- denotes that the attribute did not feature as a key priority for any segment

4.

UNDERSTANDING PATIENT PROFILES

There should be one place that I can go to. But at the moment my notes are getting shunted around from place to place to place—COPD

Communication is very low on the list. This has changed a lot since the CCG took over—Diabetes

LENS 2

4.1

PATIENT PROFILES **UNDERSTANDING** COMMON PRIORITIES

This section isolates themes that can be considered common to all LTC and protected characteristics groups engaged through this project.

In many cases, a single priority can manifest itself in ways that are highly specific to a condition or characteristic. This more finely-grained analysis will be the subject of section 4.

There should be one place that I can go to. But at the moment my notes are getting shunted around from place to place to place—COPD

Communication is very low on the list. This has changed a lot since the CCG took over—Diabetes

PATIENT PROFILES

COMMON PRIORITIES

ENGAGEMENT BUILDS SATISFACTION

- There was a positive response to engagement across all groups.
- There is a desire for more opportunities to shape service.
- Future engagement efforts would benefit from a deeper penetration into patient communities:

1. Reducing reliance on expert patients and existing groups and reaching out to more representative citizen-patients.
2. Using more tightly defined demographic and attitudinal segmentation.

They [the CCG] deserve credit for running these meetings. For once, I feel like I've actually been listened to—*Diabetes*

There should be more of these meetings. I know loads of people who would be interested in taking part—*MH*

I know we've had a good old whinge, but they're not doing a bad job. At least they're listening to what we have to say—*COPD*

It's not us you need to be talking to. We know how to get our care. It's those with low social skills and vulnerable people that you need to talk to—*Diabetes*

NEMS

PATIENT PROFILES

COMMON PRIORITIES

INDIVIDUAL NEEDS

- Frustration mounts when systems and staff fail to respond adequately to individual needs.
- This is most commonly manifested in the failure of staff with ***generalist expertise*** to respond appropriately to a ***specific condition***.
- This perceived lack of sensitivity can have significant impacts on episode satisfaction.
- When this experience is repeated across multiple episodes this impacts dramatically on overall satisfaction.
- Applies to both **specific conditions.**

These people should be trained to at least recognise the problem—*Diabetes*

It's such a common condition. All staff such know more about it—*COPD*

If you have a broken arm, A&E are fine. But if you have a mental illness, they don't have a clue—*MH*

But when I saw a CPN—they had the knowledge and I got well because of them—*MH*

PATIENT PROFILES

COMMON PRIORITIES

INDIVIDUAL NEEDS

- Frustration mounts when systems and staff fail to respond adequately to individual needs.
- This is most commonly manifested in the failure of staff with ***generalist expertise*** to respond appropriately to a ***specific condition***.
- This perceived lack of sensitivity can have significant impacts on episode satisfaction.
- When this experience is repeated across multiple episodes this impacts dramatically on overall satisfaction.
- …and **protected characteristics.**

Hospitals do not cater for the black community—BME/AC

Female patients needs female doctors—BME/ASIAN

GPs need training on the needs of young people to include how they should be treated—CYP

They need to provide LGBT training for staff who need to support LGBT people.—LGBT

The district nurse didn't understand that patient with no speech didn't mean not consenting—LD

NEMS

PATIENT PROFILES

COMMON PRIORITIES

COMMUNICATION: CHANGES

- Communication regarding the future of services was deemed poor across all groups.
- This causes uncertainty and insecurity that creates background dissatisfaction.
- A number of 'expert patients' felt strongly that their dissatisfaction had increased since the CCG took over from the PCT.
- CYP didn't reflect this theme, potentially as a result of their greater use of digital communications and social media.

You worry about what's going to happen next. This just seems to change and nobody lets us know—*MH*

Communication is very low on the list. This has changed a lot since the CCG took over—*Diabetes*

We only find out when we go and it has closed—*ME*

My GP retired – no one told me—*PD*

The responsibility for commissioning has changed and now we don't know who is responsible for providing what service!—*Carers*

PATIENT PROFILES

COMMON PRIORITIES

RESPECT & DIGNITY

- A source of dissatisfaction for all groups, but specific manifestations for specific groups—see 'burning issues'.
- Partially driven by the age profile of some groups.
- In other cases (Mental Health, Dementia) driven by the extent to which the diagnosis can depersonalise the individual needs of a patient.
- Conditions that require a patient to have a carer, advocate or support worker also create respect & dignity risks that staff need to be aware of.

They need to make you feel like you belong—*MH*

They never listen; never ever listen. Basic communication skills are not taught at the induction (nurses, reception staff etc)—*COPD*

We have lived with our disabilities and ailments most of our lives – do not treat us like idiots—*PD*

Them telling your parents when you are sat there – not good—*CYP*

NEMS

PATIENT PROFILES

COMMON PRIORITIES

RECEPTIONISTS

- A uniform dissatisfaction expressed in relation to receptionists.
    - General attitude and communication skills
    - Intrusive questioning
    - Trying to assume clinical roles above their station.
- Some patients sympathised with the lot of the receptionist in the context of abuse and rudeness from patients and soften their opinion.

If you go to hospital Reception is the worst thing. If you go to GP the receptionist is the worst thing and they are the face of the institution—*COPD*

GP receptionists should treat young people better – more respect—CYP

My GP receptionist thinks she is a doctor and won't let me see my GP without grilling me first!—BME/AC

They're just nosey!—BME/ROM

But if I had to put up with what they have to I think I'd be a bit grumpy—*Diabetes*

PATIENT PROFILES

COMMON PRIORITIES

CONTINUITY OF CARE

- On-going care/regular consultations creates priority for continuity of care
- Seeing different people in different settings results in disjointed care, repetition and confusion.
- This series of negative episodes has a cumulative effect on overall satisfaction
  - Frustration at having to repeat medical histories
  - Mistrust of diagnoses
  - Even adverse clinical outcomes.

People you've never met before are making decisions on you. It doesn't feel right—*MH*

When I see different people it is clear they have not read my notes and this concerns me about the treatment I will receive—*VI*

You don't feel like you're moving forward [when you're talking to different people]; just constantly repeating yourself—*MH*

Every specialist you go to asks what medicines are you on—it's so frustrating, surely they should know—*Diabetes*

NEMS

PATIENT PROFILES

COMMON PRIORITIES

COORDINATION OF CARE

- When managing multiple conditions, coordination of care becomes a priority.
- There was a desire for consultants to treat the person, not the condition(s).
- Results in a failure to account for how a long-term condition affects the treatment of other conditions or access to other services.
- A clear tension emerging between wanting specialist services and holistic care.

There should be one place that I can go to. But at the moment my notes are getting shunted around from place to place to place—*COPD*

Something as simple as getting an eye test becomes impossible [with a dementia sufferer], but people don’t realise this—*Dementia*

Services need to work together to ensure that people with LD are not neglected in anyway, repeat prescriptions, appointments, transport, social services, support groups, etc—*LD*

PATIENT PROFILES

COMMON PRIORITIES

COMMUNITY SUPPORT

- All groups with long-term conditions were both reliant on community support and anxious about future provision.
- Dissatisfaction results from:

    1. Positive experience of third sector help.
    2. Perception that CCG (or generically NHS) are responsible for cutting funding.

It's the activities and seeing people—I won't get better if I haven't got the social aspect—*MH*

Without [support service coordinator] I just don't know where I'd be. I owe her everything—*Dementia*

Third sector needs more recognition and support. Especially now we've brought together health and social care—*Diabetes*

Everything for people with ME is closing and nothing is replacing it—*ME*

NEMS

PATIENT PROFILES

COMMON PRIORITIES

WAITING TIMES

- A priority and source of dissatisfaction across most groups.
- Possibly a ***salient*** issue rather than a ***significant*** one, driven by media coverage and political emphasis.
- In the context of specific conditions—notably dementia, mental health and learning difficulties—waiting times were a salient ***and*** significant source of (dis)satisfaction. See 'Burning Issues' below.

By the time I've waited 5 months for an appointment I could have gone through so many different phases—*MH*

The longer you have to wait, the more you suffer—*MH*

My GP kept me waiting so long I had to walk out because I was so stressed—*LD*

People with LD do not like to wait for long periods of time as this makes them anxious—*LD*

She doesn't understand why we're waiting. She gets stressed. And there's nothing I can do with her—*Dementia*

PATIENT PROFILES

COMMON PRIORITIES

SIGNPOSTING

- Many patients not accessing support services simply because they aren't being signposted.
- Improved signposting could potentially represent a source of increased satisfaction that is relatively easy to tap into.

The GP should be able to signpost, but that isn't happening—*MH*

I haven't been told what services are in my community—*LD*

We don't know what there is [in our community]—LGBT Chorley

I didn't know about this [Minerva Centre]—Elderly

NEMS

PATIENT PROFILES

COMMON PRIORITIES

NO POINT OF CONTACT

- Frustration and feelings of isolation result when there is no appropriate first point of contact.
- Applies across service, from emergency treatment or information and signposting.
- In many cases, GP and A&E are the only options.

There's just no one to call—it's very opaque—*Diabetes*

With the council you have a list of things—council tax, bin collections etc—and a number next to it. Why can't we have one of those for diabetes?—*Diabetes*

It's much more urgent [than a general complaint], so you need someone you can contact for help—*COPD*

You've no choice but to go to A&E, but they don't want to know you—*MH*

NEMS

PATIENT PROFILES

COMMON PRIORITIES

PERCEIVED WASTE

- A number of participants across several groups expressed frustration with perceived waste in the system.
- More specifically a liberal distribution of equipment and a reluctance to re-use or recycle it after use.
- Others highlighted more general issues with how the NHS is structured and how roles/salaries are distributed between management and clinical staff.

There is too much waste in the system. We were told to throw away or sell the equipment we got when we have finished with it!—Christian

Re-cycle equipment that has not been used. There's too much waste—*COPD*

Get rid of the waste in the system—stop buying new chairs!—*PD*

They don't re-use or take back equipment—*PD*

NEMS

PATIENT PROFILES **UNDERSTANDING** SPECIFIC CONDITIONS

To make the qualitative findings as actionable as possible within a planning context, this section highlights the two main ***priorities*** for ***each*** LTC/protected characteristic profile, based on thematic analysis.

It then goes on, where appropriate, to highlight other ***concerns:*** themes of note that also emerged, but with less frequency and/or depth of feeling than the ***priorities.***

In relation to patients with protected characteristics, we have reported ***priorities*** only, due to limitations in the data.

They think we're fat cows who've done it to ourselves—*Diabetes*

GPs see ME as a mental health problem – I don't, I don't want to be given anti-depressants—*ME*

4.2

PATIENT PROFILES
UNDERSTANDING
MENTAL HEALTH

"The longer you have to wait, the more you suffer."

"Mental health is at the bottom of the list of priorities—it's pushed to one side and forgotten about."

MENTAL HEALTH

PRIORITIES

SECOND-CLASS PATIENTS

- There was a general and unanimous sense that mental health sufferers are treated as second-class patients compared with their physically ill counterparts.

People with mental health problems are just being pushed to one side.

Mental health is at the bottom of the list of priorities—it's pushed to one side and forgotten about.

There's loads of money going to cancer and heart disease, but less and less into mental health.

They're frightened you're going to take a bed up.

MENTAL HEALTH

PRIORITIES

WAITING TIMES: SPECIFIC IMPLICATIONS FOR MENTAL HEALTH SUFFERERS.

- The nature of many mental health conditions means that waiting times are a particular priority for many sufferers.
- Untreated episodes can escalate quickly and stressful service scenarios can often accelerate this.
- The group felt that generalist staff did not understand the urgency of their episodes and treated physical conditions as more important.

I wait months for an appointment. By the time I've waited 5 months I could have gone through so many different phases.

The longer you have to wait, the more you suffer.

I once waited 6 months to get appointment with a CPN.

I've gone into A&E saying I feel suicidal and then been put in a broom cupboard and made to wait 5 to 12 to 18 hours.

MENTAL HEALTH

CONCERNS

ACCESS: POINT OF CONTACT

- Frustration and isolation results from the fact that there is no appropriate first point of contact, whether for emergency treatment or just information and signposting.
- In many cases, GP and A&E are the only options, but often neither is adequate due to the specific nature of the condition/episode and the amount of waiting involved.
- A dedicated point of contact would not only positively affect satisfaction, but would also ease pressure on resources.
- A patient can be more quickly, appropriately signposted or given a brief intervention (discussion) that removes the need for service.

GPs don't have time. They can't sit and talk to you if you're going through a bad episode.

You've no choice but to go to A&E, but they don't want to know you.

If they took the time to talk to me then I probably wouldn't need admitting.

MENTAL HEALTH

CONCERNS

CONSULTATION: GENERAL EXPERTISE FOR SPECIFIC CONDITION

- Frustration mounts when consultations are with generalist, rather than specialist staff who aren't adequately trained/sensitive to the particular needs of mental health sufferers.
- This frustration intensifies in emergency situations, where a combination of specific need and generalist response quickly leads to enduring diminished satisfaction.
- Increased awareness and training amongst generalist staff would help with this dynamic, but a dedicated point of contact could potentially serve the same purpose more cost-effectively.

GPs don't have much knowledge about mental health.

If you have a broken arm, [A&E] are fine. But if you have a mental illness, they don't have a clue.

But when I saw a CPN—they had the knowledge and I got well because of them.

NEMS

MENTAL HEALTH

CONCERNS

DISCHARGE: TIMING / PLANNING

- Some members of the group felt they had been discharged too early and without adequate after-care planning.
- This not only resulted in diminished satisfaction, but also in subsequent episodes and re-admittance, which in turn diminished satisfaction further still, whilst putting further pressure on resources.
- They felt it crucial to ensure they were kept in service long enough to be stabilised properly.

If they'd have let me stay for long enough to get stable—not too long, but the right amount, I might have been ok.

They sent me home too early so I ended up back in again a few days later.

MENTAL HEALTH

CONCERNS

DISCHARGE: PLANNING

- In addition to the timing of discharge, the whole group highlighted the importance of a well-planned discharge, with adequate and considered provision of follow-up and on-going support.
- Some felt that the service had ‘chucked them out’ and left them to fend for themselves.
- A younger member of the group simply couldn’t believe how we could be sent home with medication, but without a coordinated follow-up plan.
- Premature discharge with rushed or haphazard planning was felt to be part of a wider issue related to the lower priority placed on mental health patients and a sense that services just want them “off their plate.”

A care plan that has been thought through and discussed with you. Not just scribbled down at two in the morning.

I had nowhere to go—they hadn’t thought it through. I was in Blackpool with no money and the hostel they sent me to had shut down.

There is no follow up. You’re just left to your own devices.

MENTAL HEALTH

CONCERNS

DIGNITY & RESPECT: STIGMA

- Apart from community care, dignity and respect was the key determinant of satisfaction within this group and ran through every contact with service, from GP to A&E to community care.
- The group felt that they were treated as *mentally ill people*, rather than *people with mental problems.* A sense that the label blinded others to the rest of their personality and their other needs.
- In particular, it was felt that this applied to healthcare settings with professionals, as well as society at large with the general public.
- At a very general level, they felt stigmatised and were frustrated that more wasn't being done to combat this.

If only they could treat it like a normal illness instead of this oh you've got *mental* illness.

The thing with mental health is that people think you're stupid, and it's far from it.

They need to make you feel like you belong.

They've already decided what they're going to do with you.

MENTAL HEALTH

CONCERNS

DIGNITY & RESPECT: TREATMENT

- A more specific 'dignity & respect' frustration related to treatment methods.
- Many felt as though consultants were merely medicating the condition, rather than treating the person.
- They related this back to both increasing time pressures and the greater priority placed on physical illness: writing a prescription was a quicker and easier way of getting the case 'off their desk'.
- Given the individual nature and complexity of many mental health issues, this impersonal approach led to patients feeling overlooked or even de-humanised.

“”

Sometimes when you're being treated in the NHS, it's a matter of that injection, that tablet and then get lost.

It's like, 'take that and bugger off!'.

NEMS

MENTAL HEALTH

CONCERNS

DIGNITY & RESPECT: INDIVIDUAL DIFFERENCES

- Again, given the specific and personal nature of many mental health disorders, some participants felt that services have a tendency to overlook individual differences.
- ‘Mental health’ is a label that is often applied indiscriminately to cases that vary greatly in symptoms and severity.
- This can leave patients feeling de-individualised and in some cases can contribute to further escalation of an episode or the decline of a condition.

I don’t see how they could bring me in with a mild condition and have me sit in a room with loads of people who are really far gone.

Seeing people being carried off by the police in riot gear—it’s not good for you own mental health.

MENTAL HEALTH

CONCERNS

COMMUNITY SUPPORT

- Whilst the group recognised the importance of balancing hospital and community care, they were most concerned about current and future changes in community support services.

It's the social side of things. You need activities to keep you occupied and they're not being provided.

I got sectioned, but the thing that's going to get me through it is the social aspect.

It's the activities and seeing people—I won't get better if I haven't got the social aspect.

MENTAL HEALTH

CONCERNS

COMMUNITY SUPPORT

- Whilst the group recognised the importance of balancing hospital and community care, they were most concerned about current and future changes in community support services.
- There is recognition that services are being cut…

Mind are brilliant, but because of cuts it got shut down. It was brilliant.

There's just less and less to do. You're left to your own devices a lot more.

Activities through support centres—they've all gone now. It's just assessment centres.

MENTAL HEALTH

CONCERNS

COMMUNITY SUPPORT

- Whilst the group recognised the importance of balancing hospital and community care, they were most concerned about current and future changes in community support services.
- There is recognition that services are being cut…
- …but also that GPs and other services aren't referring effectively to the community support that is available.

The GP should be able to signpost, but that isn't happening.

MENTAL HEALTH

CONCERNS

CONTINUITY OF CARE

- Seeing lots of different people in different settings results in disjointed care, repetition and confusion. In turn this has a significant impact on satisfaction.
- Given that many mental health conditions manifest differently for different patients and that service access is often unpredictable and ad-hoc, mental health sufferers are potentially the patients most in need of continuity of care, yet least likely to receive it.

People you've never met before are making decisions on you. It doesn't feel right.

You don't feel like you're moving forward [when you're talking to different people]; just constantly repeating yourself. someone—one person—needs to be accountable for you from the beginning to the end of your treatment.

It's important that there's continuity with the case. It keeps us informed and the professional up-to-speed.

NEMS

MENTAL HEALTH

CONCERNS

CONTINUITY OF CARE

- Seeing lots of different people in different settings results in disjointed care, repetition and confusion. In turn this has a significant impact on satisfaction.
- Given many mental health conditions services manifest differently for different patients and that service access is often unpredictable and ad-hoc, mental health sufferers are potentially the patients most in need of continuity of care, yet least likely to receive it.
- Some in the group noted that this had recently been exacerbated by an increase in agency staff.

They're in Blackburn one day, Burnley the next… they don't know the first thing about who they are seeing.

They've got that many people to go to, they're spending as little time as possible with each one.

NEMS

4.3

PATIENT PROFILES
UNDERSTANDING
COPD

"The care was good… when they finally found out what was wrong with me."

"They never listen; never ever listen. Basic communication skills are not taught at the induction."

NEMS

COPD

PRIORITIES

BEING LISTENED TO

- A key source of dissatisfaction for the COPD group related to the attitude of NHS staff and their ability to listen attentively.
- This applied equally to clinical and non-clinical staff.
- It is impossible to tell whether this is specifc to COPD sufferers or a more general reflection of the expectations of older patients.

If you go to hospital Reception is the worst thing. If you go to GP the receptionist is the worst thing and they are the face of the institution.

You need a good bedside manner—I agree with that!

They're using a language that just isn't appropriate or understandable for older people like us.

They never listen; never ever listen. Basic communication skills are not taught at the induction.

NEMS

COPD

PRIORITIES

DIAGNOSIS

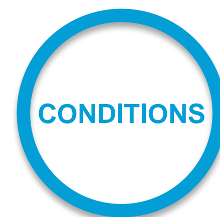
- A number of the group outlined how their diagnosis had been slow or convoluted. They felt that because COPD is not a specific condition, it is more likely to go undiagnosed for longer than other conditions.

My diagnosis happened in a very roundabout way. I went in with prostate cancer but had a cough. It took them months to get to the bottom of it.
I was going between Preston and Chorley for over 18 months before they found out what was wrong with me.

The care was good… when they finally found out what was wrong with me.

COPD

PRIORITIES



DIAGNOSIS

- A number of the group outlined how their diagnosis had been slow or convoluted. They felt that because COPD is not a specific condition, it is more likely to go undiagnosed for longer than other conditions.
- Others felt strongly that earlier diagnosis is particularly important for COPD sufferers, given the impact it can have on other conditions and day-to-day life.

They need to get it [COPD] diagnosed earlier!

If they could have spotted that sooner and got me sorted, I wouldn't have developed sleep apnoea as much as I did and therefore I wouldn't have lost my job and everything else.

COPD

PRIORITIES

DIAGNOSIS

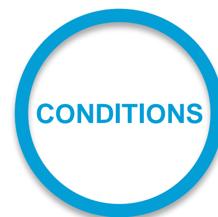
- A number of the group outlined how their diagnosis had been slow or convoluted. They felt that because COPD is not a specific condition, it is more likely to go undiagnosed for longer than other conditions.
- Others felt strongly that earlier diagnosis is particularly important for COPD sufferers, given the impact it can have on other conditions and day-to-day life.
- A suggestion that there needs to be more pro-active outreach to locate COPD sufferers earlier was met with unanimous support.

I was diagnosed when someone at the Health Mela told me I had a lung age of 113.

We should have more equipment available out in the community at church meetings, health melas etc.

COPD

CONCERNS



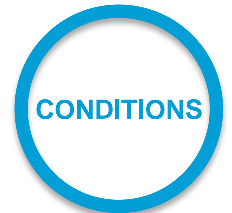
DIGNITY & RESPECT: EXPECTATIONS

- In general, being treated with respect and dignity is by far the main source of dissatisfaction for this group.
- However, it is difficult to suggest a correlation with their condition, as there was no sense that negative experiences in this regard were linked directly services specific to COPD.
- It is more likely to be a reflection of patient needs generally, with an increased emphasis due to the age of the participants, i.e. older people expecting more respect by virtue of their seniority, but also due to the perceived respect and friendliness that was characteristic of their generation.

It's not how it used to be. People just don't listen or talk to you in the same way.

COPD

CONCERNS



DIGNITY & RESPECT: CLINICAL OUTCOMES

- Some went as far as recognising the link between emotional experience and clinical outcomes.
- Some suggested that the stress of counter-intuitive processes, combined with impersonal treatment results in further physical deterioration and, ultimately, increased pressure on resources as a result.

The stress of all that, they reckon contributed the stress which contributed to my heart problem.

It’s terrible. You go in with great expectations but you come back with nothing but frustration and then you go down further.

COPD

CONCERNS

DIGNITY & RESPECT: STAFF ATTITUDES

- Many participants expressed dissatisfaction with the attitude of NHS staff, with particularly harsh opinions regarding receptionists.

If you go to hospital Reception is the worst thing. If you go to GP the receptionist is the worst thing and they are the face of the institution.

They treat you like dirt.

COPD

CONCERNS

DIGNITY & RESPECT: STAFF ATTITUDES

- Many participants expressed dissatisfaction with the attitude of NHS staff, with particularly harsh opinions regarding receptionists.
- The group highlighted basic shortcomings in interpersonal skills with both clinical and non-clinical staff.
- They felt that the medical focus of clinicians led to a lack of 'bedside manner' and that the age gap between them and many of the non-clinical staff resulted in a lack of empathy.

You need a good bedside manner—I agree with that!

Some of the most brilliant consultants and academics I've met just don't have a bedside manner.

They're using a language that just isn't appropriate or understandable for older people like us.

COPD

CONCERNS

DIGNITY & RESPECT: FEELING RUSHED.

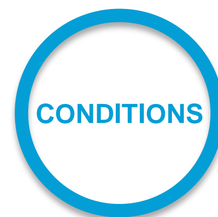
- The group was similarly unanimous regarding the feeling of being rushed during consultations.
- This led to a sense that they weren't being listened to and exacerbated worries that this lack of attentiveness could result in inferior clinical outcomes.

They just don't seem to have the time for you (when you go to hospital) and it's much worse at Preston than Chorley.

They haven't enough time—it's targets and through-puts. It makes them more interested in the target than you.

COPD

CONCERNS



DIGNITY & RESPECT:

- The group was similarly unanimous regarding the a feeling of being rushed during consultations.
- A separate, but related, point emerged in relation to a perceived lack of attentiveness on the part of the clinician. This has resulted in both psychological frustration and clinical error.

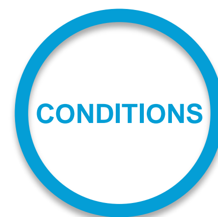
I told her I couldn't have steroids, but then she made me a prescription for something that had steroids in it!

What you're saying is true, they don't seem to listen.

They never listen; never ever listen. Basic communication skills are not taught at the induction (nurses, reception staff etc).

COPD

CONCERNS



CONTINUITY OF CARE

- Because COPD is an on-going, irreversible condition, continuity of care was of particular importance to this group.
- The practical implications of this frustrates participants in terms of repeating treatment histories and enduring extended waits to see a chosen doctor.

I want to see the same person, otherwise you've no idea what's going on.

When you go to hospital, the doctor gives you an appointment, but you know that it's going to be another doctor by the time you go for it.

If you want to see the same doctor (GP) you'll need to wait three weeks for your appointment, so you end up just seeing whoever is available next.

COPD

CONCERNS

CONTINUITY OF CARE

- Because COPD is an on-going, irreversible condition, continuity of care was of particular importance to this group.
- The practical implications of this frustrates participants in terms of repeating treatment histories and enduring extended waits to see a chosen doctor.
- However, the emotional consequences are at least as important in relation to patient satisfaction.

You feel better if you get to know them over time. When they know you a bit you feel like they're doing more than just processing you.

I like to get to know a doctor… to feel like they're looking after you, not just giving you pills and equipment.

COPD

CONCERNS

CONTINUITY OF CARE

- Because COPD is an on-going, irreversible condition, continuity of care was of particular importance to this group.
- The practical implications of this frustrated participants in terms of repeating treatment histories and enduring extended waits to see a chosen doctor.
- However, the emotional consequences are at least as important in relation to patient satisfaction.
- It also resulted in diminished confidence regarding diagnosis and treatment.

I'd have more confidence in him or him (i.e. other sufferers) than the doctor.

All the doctors that you trusted and depended on are gone.

I can't honestly say that I'd trust any of them.

COPD

CONCERNS

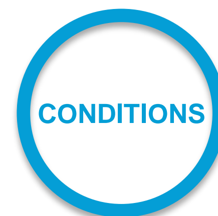
CONSULTATION: GENERAL EXPERTISE FOR SPECIFIC CONDITIONS.

- As with other long-term conditions, participants felt that the level of understanding of the specific needs of COPD sufferers was poor across services.

It's such a common condition. All staff should know more about it.

COPD

CONCERNS



CONSULTATION: GENERAL EXPERTISE FOR SPECIFIC CONDITIONS.

- As with other long-term conditions, participants felt that the level of understanding of the specific needs of COPD sufferers was poor across services.
- Frustration resulted when trying to get assistance from general services.

Why don't they have a chest ward in the hospital so you can get specific treatment?

There should be a COPD clinic in the GP surgery.

4.4

PATIENT PROFILES **UNDERSTANDING** DIABETES

"They think we're fat cows who've done it to ourselves."

"Those with low social skills, just get piled up with leaflets and sent away."

DIABETES

PRIORITIES

HEALTH INEQUALITIES & PATIENT EMPOWERMENT

- All bar one of the Diabetes group were expert patients.
- As such, they brought a perspective on treatment of diabetes suffers generally, rather than simply their own specific patient experience.
- One of the strongest themes was the need for a more targeted and tailored approach to minority or vulnerable patients and pro-active approaches to empowering them.

Those with low social skills, just get piled up with leaflets and sent away. They got no education or help to understand. They went away feeling completely lost.

If you're vulnerable, illiterate or have English as a second language, you're just persecuted for that and you're not going to get any real care.

There are so many people who aren't educated to understand what they should be getting, so they don't get it.

DIABETES

PRIORITIES

STIGMA

- The increase in media-fuelled stigma around diabetes is becoming an important priority for sufferers.
- It affects their levels of satisfaction in two ways:

1. They feel stigmatised even by (ill-informed) NHS staff and…
2. They feel the NHS could being doing more reduce stigma amongst the public.

They think we're fat cows who've done it to ourselves.

It's an embarrassment, because people presume you're a fat slob.

Everything that's going on in the press, it does filter down to staff.

The first thing is staff training. Staff need educating about the realities of diabetes.

It's political. They could be doing more [to reduce stigma]. But if people think it's our own fault it makes it easier for them to cut back our services.

DIABETES

CONCERNS

SPECIALIST SERVICES

- Given that diabetes creates other healthcare needs, such as foot and eye health, this group felt they had a wider context of need than some other conditions.
- As a result, they placed a particular priority on diabetics being able to access services related to the wider specific needs that the condition entails.
- Retinal scanning emerged as an important service, but provision of easy-to-access, high quality podiatry was considered essential.
- There was a general perception that the quality of this service was in decline. This causes worry and dissatisfaction.

Podiatry is more than a key thing. It is the essential factor. Feet care for diabetes is critical.

To me it's very important. At least I'm reassured and I know that the service is there as and when I need it.

The last two times I've been, they've drawn blood at the side of the toe!

We fought for years to get retinal screening and it has been a great success.

DIABETES

CONCERNS

QUALITY OF CARE: GENERAL EXPERTISE FOR SPECIFIC CONDITIONS

- As with other LTCs, there was a widespread sense that when interfacing with general health care services—especially in hospital—there was a lack of specific understanding and expertise in relation to diabetes.
- This results in frustration at inefficiencies, lack of confidence in quality of care and, ultimately, physical danger.

They were brilliant at dealing with the heart side of it, but the diabetes care was absolutely crap. It's not right!

These people should be trained to at least recognise the problem.

They thought he was drunk, so they called the police. The poor guy went to all that trauma, and he'd just gone into hypo.

DIABETES

CONCERNS

QUALITY OF CARE: GENERAL EXPERTISE FOR SPECIFIC CONDITIONS

- As with other LTCs, there was a widespread sense that when interfacing with general health care services—especially in hospital—there was a lack of specific understanding and expertise in relation to diabetes.
- This results in frustration at inefficiencies, lack of confidence in quality of care and, ultimately, physical danger.
- Hospital passport is essential to coordinate care of the condition, but isn't being used.

If you go in with [a hospital passport], the staff know exactly what your needs are. But it's a voluntary thing.

But they don't know what to do with it and they don't use it.

DIABETES

CONCERNS

QUALITY OF CARE: GENERAL EXPERTISE FOR SPECIFIC CONDITIONS

- As with other LTCs, there was a widespread sense that when interfacing with general health care services—especially in hospital—there was a lack of specific understanding and expertise in relation to diabetes.
- This results in frustration at inefficiencies, lack of confidence in quality of care and, ultimately, physical danger.
- Hospital passport is essential to coordinate care of the condition, but isn't being used.
- This is a high priority issue, but is considered to be relatively easy to remedy and could therefore offer significant opportunity for increased satisfaction.

It's really not that difficult to grasp the basics of diabetic care.

It's crazy, because these people used to get trained around these things.

People with diabetes are living longer, but care home staff don't know how to deal with diabetes.

DIABETES

CONCERNS

ACCESS: MAKING CONTACT

- There was a general sense of isolation in the group as they felt there was no responsive/effective point of contact, given their specific needs as diabetes sufferers.
- This reflected the wider point about frustrations associated with general expertise in the context of specific conditions and covered emergency help.
- Again, the perceived relative simplicity with which this issue could be addressed compounds the dissatisfaction with actual service.

There's just no one to call—it's very opaque.

Who do we turn to in an emergency?

If you want to complain, there's just a sense that there's nowhere to go.

With the council you have a list of things—council tax, bin collections etc—and a number next to it. Why can't we have one of those for diabetes?

All it needs is a helpline, but one that is manned by a knowledgeable person at the other end.

DIABETES

CONCERNS

COORDINATION OF CARE

- The entire group were frustrated that their diabetes (and other conditions) were separated off into multiple silos.
- Practically, this resulted in frustration at the inconvenience of seeing different people on different days.
- Emotionally it created a sense that the doctor is only interested in treating the condition and not the person.

Every specialist you go to asks what medicines are you on—it's so frustrating, surely they should know?

If she's going to be seen for her heart, she might as well be seen for her diabetes at the same time.

Or have someone who has some feeling for what's going on with her as a whole, rather than her being like a ping pong ball.

If you could go to one place and get everything done in a day… I know it's a whole day, but you're all sorted.

4.5

PATIENT PROFILES **UNDERSTANDING** DEMENTIA

"They made us wait 2 hours, by which time she was down to her corset!"

"Nobody could see that this gentleman [the carer] was cracking up in front of them."

NEMS

DEMENTIA

PRIORITIES

SERVICE 'UNDERSTANDING'

- A key source of dissatisfaction that carers don't feel is being acknowledged.
- A lack of tailored provision for dementia sufferers in relation to their wider healthcare needs.
- Forcing a dementia sufferer through mainstream services, with the associated busy/stressful waiting rooms, waiting times, complicated procedures etc causes distress for carer and sufferer alike.
- This is being overlooked by the service.

She doesn't know why she's having to wait, so she'll end up having going off [having an episode].

Something as simple as getting an eye test becomes impossible [with a dementia sufferer], but people don't realise this.

NEMS

DEMENTIA

PRIORITIES

CARER SUPPORT

- Representation at the Dementia group was made up entirely of carers.
- The main opportunity for an increase in satisfaction amongst this group related to the support that they receive to care for their loved ones.
- Underneath this was considerable concern over the plight of the third sector, given that the this was their most valued source of social support.

With sounding selfish, it's me that needs the help. [Dementia sufferer] is fine—she doesn't know what's going on. But I'm the one that's at breaking point.

It's these people [carers] I worry about. They need help and it's just not there.

If these go down, your healthcare budget is going to rocket.

Nobody could see that this gentleman [the carer] was cracking up in front of them.

DEMENTIA

PRIORITIES

SERVICE: THIRD SECTOR

- Building on the previous point, the role of the third sector is fundamental to this group.
- They feel the majority of the support they require relates to non-clinical matters and that the NHS is simply not helping with this.
- Understandably, they worry that the third sector, and the essential support they receive from it, will suffer as part of planned changes.
- Even where services are available there is still an issue with signposting, especially from GPs.

Age Concern: it's fantastic what they are doing. It's a god send. It gives us something to look forward to.

To be honest, we get little support from NHS.

The Alzheimer's Society is superb in every respect, they can't do enough.

Without Genesis [support group], I'd be in hospital.

People don't know about services.

Nobody told me about Genesis—I heard someone talking about them.

DEMENTIA

CONCERNS

QUALITY OF CARE: GENERALIST EXPERTISE FOR SPECIFIC CONDITIONS

- As with other LTCs, the extent to which service was perceived to lack sensitivity to the needs of dementia sufferers/carers is a key source of dissatisfaction.
- This was felt to be the case across all service touch points, but was felt most acutely with the GP.
- There was a pronounced desire for more training to increase awareness and sensitivity.

There's a lot of GPs who don't know what to do with dementia or don't know what dementia is.

Everyone from doctors down to porters are meant to have dementia training. Do you feel they understand the condition when you deal with them? No, not at all.

There's a massive need for further training and awareness.

NEMS

DEMENTIA

CONCERNS

QUALITY OF CARE: GENERALIST EXPERTISE FOR SPECIFIC CONDITIONS

- The lack of awareness and understanding of the conditions means that services simply are not responsive to dementia sufferers and their carers, across a number of areas:
  - *Waiting times*: sufferers become frustrated and difficult to handle when kept waiting.
  - *Waiting environments*: sufferers are agitated by busy/noisy environments.
  - *Facilities to allow carer into consultation*: sufferers cannot function alone.

“”

They made us wait 2 hours [for a foot appointment], by which time she was down to her corset! [sufferer had been taking clothes off].

The atmosphere needs to be friendly, comfortable.

[sufferer] went for a breast scan. It was impossible for them to scan her because she had to go in on her own.

There’s just no way that [sufferer] could have an eye test. She wouldn’t have a clue. She wouldn’t answer anything.

DEMENTIA

CONCERNS

QUALITY OF CARE: GENERALIST EXPERTISE FOR SPECIFIC CONDITIONS

- More generally, there was a sense that this lack of sensitivity/understanding from generalist staff results in them simply not trying hard enough or going far enough to respond to individual needs.
- There is a tendency to ‘take their [a sufferer’s] word for it’, when anyone familiar with the condition knows that sufferers can’t articulate their own needs reliably.

They aren’t prepared to try other ways.

If they don’t respond to a normal approach they give up (eg getting a patient to eat). They don’t have the time to sit with them and try different things.

When they say ‘no’, they take ‘no’ for an answer, but they say no to everything.

They don’t say what they mean. If they say no to having something to eat, it’s not because they’re not hungry. You have to try harder to get them to eat.

NEMS

DEMENTIA

CONCERNS

CONTINUITY OF CARE

- Whilst this has emerged as an issue for most LTC groups, it has a specific impact for dementia sufferers and their carers.
- Given that confusion and lack of continuity are significant aspects of the condition itself, consistency is considered particularly important for this group.
- As with other groups, in addition to frustration, this also leads to a lack of confidence in the quality of clinical care.

For someone who gets confused at the best of times, seeing someone different every time is really unsettling.

Because of all the changes… you used to have [one] doctor, but now you don't unless you insist on the seeing the same one.

It gets me annoyed—nobody seems to take a lot of interest.

I'm assured that they have all the information, but I'm dubious.

DEMENTIA

CONCERNS

COORDINATION OF CARE

- There was a unanimous sense that current service lacks coordination across the various healthcare needs of dementia sufferers.
- Practically, this had resulted (surprisingly, for all participants) in at least one instance of notes being lost.
- Emotionally, it results in a sense that there is no one to turn to, especially given that generalist services are time-poor, ill-equipped to understand the specific needs of dementia patients or, in some cases, both.

There's nobody to take the time to understand the full picture. Everybody's only interested in their own bit.

They're always losing records.

More than frustrating. If the consultant doesn't have the right information then you get nowhere.

You've got all these leaflets, but when something goes wrong, they're useless. You need that one person to talk to.

DEMENTIA

CONCERNS

EFFECTIVE ADVOCACY

- Protocols related to human rights, patient privacy and power of attorney were seen as a significant hindrance to receiving appropriate, dementia-friendly care.
- The inability of many dementia sufferers to reliably advocate for themselves makes carer representation a pre-requisite to effective care.
- However, this is often hindered by the need for power of attorney, lack of awareness that the person is a carer of a dementia sufferer (when the enquiry is about another condition/issue) and a mis-placed concern for the sufferer's right to be addressed and involved.
- Earlier advice (on diagnosis) related to securing Power of Attorney was considered to be a key gap in this regard.

They don't know what's going on. They can't answer the questions, so the doctor can't get to a diagnosis.

Unless you have power of attorney, it is a nightmare getting anything done. Because they won't let you advocate.

They don't get advice soon enough on the important of getting power of attorney.

The first thing I ask [when they come into Genesis] is do they have power of attorney.

DEMENTIA

CONCERNS

CARER STATUS

- Building from the previous point, it was felt that systems should adapt to recognise ‘carer’ as a distinct status.
- This would then allow services and those delivering them to be more responsive to the needs of both carer and sufferer and to deliver more effective healthcare.

They need to identify carers and flag up who are carers, so that if someone rings up for an appointment they know they need to give them an appointment that fits in with their carer duties.

4.6

PATIENT PROFILES **UNDERSTANDING** PROTECTED CHARACTERISTICS

A note 'Gender Reassignment' was written across my case notes – how embarrassing!

[ME sufferers] are a struggling minority.

People with LD do not like to wait for long periods of time as this makes them anxious.

BURNING ISSUES

BME

CULTURAL SENSITIVITY

- For the BME groups involved in the process, a perceived lack of cultural sensitivity was the single most salient priority and source of dissatisfaction.
- Whilst this was primarily a matter of respect and dignity, in some cases it impacted directly on technical competence and clinical outcomes.

Hospitals tend to think BME is Asian and forget about the needs of black people.

They need to consider our cultural needs—female doctors, information in other languages, translators, food in hospital, religious times…

In my case, there may have been a mis-diagnosis due to language barriers and the lack of interpreters.

Nurses and doctors don't realise that black people have different conditions and health needs to white people.

BURNING ISSUES

BME

CLEANLINESS

- Exclusive to this group and specifically within the Afro Caribbean group, cleanliness emerged as a burning issue.

Hospitals don't appear to be as clean as they did when Matrons ran the wards.

I watched a cleaner use one mop to clean around six beds and then put it back into the bucket to clean the next bay without rinsing it.

BURNING ISSUES

CHILDREN & YOUNG PEOPLE

RESPECT & DIGNITY

- A desire to be treated with more respect from ‘establishment’ representatives.
- In particular, they were sensitive to being patronised due to their age, being talked about rather than to when parents or advocates were present.

GPs need to give young people options to be seen with / without their parents.

I would prefer to get the information myself and go to my own appointments.

Them telling your parents when you are sat there – not good.

BURNING ISSUES

CHILDREN & YOUNG PEOPLE

POSITIVITY/AWARENESS

- The CYP group was by far the most positive in relation to NHS services.
- Noticed a range of specific improvements over recent times.
- Knowledgeable about changes in the NHS and the reasons for them.
- Potentially as a result of greater engagement with digital communications platforms and social media.
- Consideration should be given to how this heightened awareness and positivity could be leveraged to generate positive WoM.

Chemists are open later now.

I was seen more quickly in A&E.

Doctors are open a little later.

Services ask how you feel and if the process was ok.

I feel well informed about the changes.

NEMS

BURNING ISSUES

LGBT

NB Whilst there was a mix of representatives within the LGBT groups, there seemed to be a disproportionate focus on gender reassignment issues, suggesting that certain individuals may have dominated.

RESPECT & DIGNITY

- Respect & dignity issues were a prominent priority for this group, with a variety of specific sources of dissatisfaction.
- Lack of sensitivity and understanding.
- Confidentiality issues.
- Data protection.

“”

I had blood tests and was called by my previous male name despite presenting as a woman.

A note ‘Gender Reassignment’ was written across my case notes – how embarrassing!

I was called into a clinic by my previous male name at Southport Hospital.

My medical records are not consistent and I am known by different names at different clinics – despite me telling them over and over again.

BURNING ISSUES

LGBT

NB Whilst there was a mix of representatives within the LGBT groups, there seemed to be a disproportionate focus on gender reassignment issues, suggesting that certain individuals may have dominated.

GP AWARENESS

- Many participants were very dissatisfied their GP.
- This resulted from a perceived lack of awareness of the issues that they faced and a lack of respect for their individuality.

“”

I don’t go to my GP because I am judged.

I don’t use my GP I use the pharmacy instead.

My GP has no knowledge of gender dysphoria.

My GP has little information for me about Trans issues, help and support.

There needs to be better access to GPs who have some knowledge of gender issues.

BURNING ISSUES

LEARNING DIFFICULTIES

PREPARATION AND PLANNING

- Patients in these groups need clear, detailed information that allows them to understand what will happen to them and to mentally prepare for it.
- In the absence of this clarity, LD patients experience feelings of severe insecurity and distress, which ultimately leads to dissatisfaction.

The doctor gave me some idea of what he was going to do to me but I need to know exactly what is going to happen.

I had an operation at Preston Hospital and no one told me I would have stitches or a dressing on my knee – I was so upset when I woke up I couldn't stop crying.

They did not explain the details straight away this worried me.

Doctors and nurses need to tell us what they are going to do to us and what this will mean to me.

BURNING ISSUES

LEARNING DIFFICULTIES

PRACTICALITIES

- LD sufferers quickly become distressed when in situations that aren't predictable and ordered.
- As such, the simple practicalities of attending services can be sources of significant dissatisfaction for this group.

My GP kept me waiting so long I had to walk out because I was so stressed.

People with LD do not like to wait for long periods of time as this makes them anxious.

My mum can never park the car.

Why can't we have treatments at a local hospital?

NEMS

BURNING ISSUES

ME / CFS

RECOGNITION

- These patients feel a basic sense that they are ignored by mainstream services.
- They feel that their condition and their needs are simply not acknowledged.
- This leads to a range of more specific frustrations related to treatment, community support and respect & dignity.

Most people use self-care because there is nothing else.

All the treatment I get is at a personal cost to me.

We are a struggling minority.

My family struggles to understand my condition. I often get told to grow up and it's all in my head and I am attention seeking.

GPs who understand ME are worth their weight in gold but they are few and far between.

BURNING ISSUES

ME / CFS

TREATMENT

- As a result of the above, ME sufferers face a range of difficulties in access effective treatment.
- ***NB. A range of other issues could be considered 'burning' for this group, including earlier diagnosis, carer support and stigma.***

GPs see ME as a mental health problem – I don't, I don't want to be given anti-depressants.

I asked for Occupational Therapy Support and to see a Dietician and I was told that unless I had CBT I could not have access to these services.

My GP keeps asking me to take anti-depressants – I believe they made me worse when I took them 15 years ago.

BURNING ISSUES

TRANSPORT

A META-ISSUE

- A group was engaged based on their transportation needs, rather than condition or characteristics.
- As such, transport should be seen a 'burning issue' that applies across conditions and characteristics.
- Given the level and strength of dissatisfaction with this element of service, it represents a priority and a potential source of increased satisfaction.
- This factor impacts on a wide range of satisfaction variables including waiting times, patient choice and respect & dignity.

Transport is the biggest problem for the NHS.

I go to Chorley Hospital and then after my appointment I am left waiting for a minimum of 2 hours to get picked up.

I have to choose services based on the available transport due to my disability – I would prefer to go to a local service but I can't get there.

I need to rely on friends and family to run me around to appointments – I feel that I am putting on them at times and can't do anything about it.

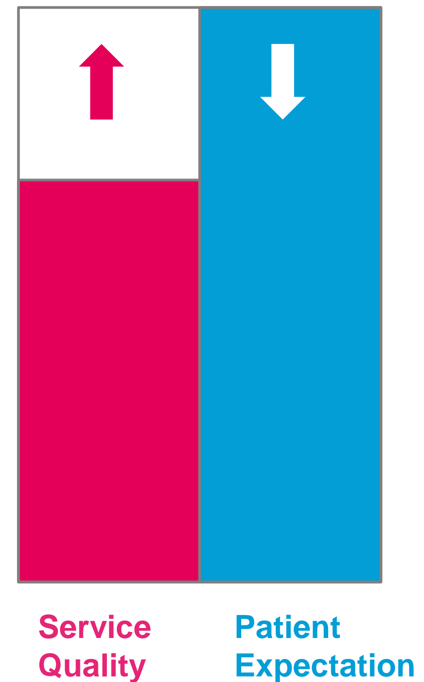
NEMS

5.

PATIENT PROFILES **INCREASING** SATISFACTION

Spend the money on decent services, not nice waiting rooms—Carer.

The NHS shouldn't try to save money – it should be free to all—PD.



INCREASING SATISFACTION

RECOMMENDATIONS

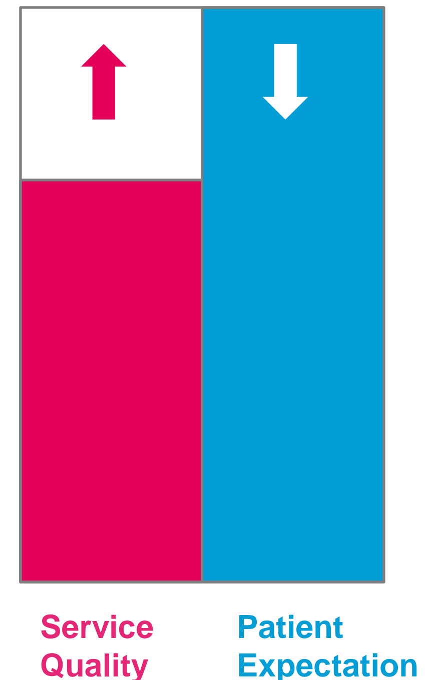
The following recommendations are based on the comments of patients engaged with this process.

We have used some discretion to extrapolate from general comments to specific recommendations, prioritising those that could potentially offer greatest ROI, i.e low cost / high impact.

Further work would be required internally and externally to assess the viability of these recommendations and develop them for application.

In line with our model of patient satisfaction they are split between managing expectations and improving service delivery.

We recommend re-engaging with patient groups and stakeholders to co-create interventions and service improvements based on the findings of this research.



INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

KNOWLEDGE AND SENSITIVITY TO SPECIFIC CONDITIONS

- Increasing awareness of specific characteristics and conditions amongst generalist staff could impact significantly on satisfaction within those groups.
- A number of groups referenced third-sector organisations who had independently created guidance packs for this exact purposes.
- Engaging third-sector organisations to produce these materials, with patient involvement, could simultaneously build relationships and increase satisfaction through greater staff sensitivity.

There needs to be a lot more training to make sure staff understand our needs—BME

We've produced the packs ourselves; they're waiting there for them to be used—*ME*

NEMS

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

POINTS OF CONTACT DEDICATED TO SPECIFIC CONDITIONS

- Amongst those with long-term conditions a single, dedicated point of contact could generate significant benefits.
- It has the potential to positively affect satisfaction whilst easing pressure on resources.
- A patient can be more quickly, appropriately signposted or given a brief intervention (discussion) that removes the need for service.

If there was someone you could ring, or even email. Someone who understands your conditions, knows what you need to do or could point you in the right direction.

If I had someone I could ring up who knew what they were talking about, I probably wouldn't need to go to A&E.

NEMS

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

COMMUNICATIONS SKILLS

- Given the high priority and dissatisfaction related to basic interpersonal skills—listening attentively, not rushing etc—an improvement in staff communication skills could yield significant, cost-effective impacts on satisfaction.
- Given the particular dissatisfaction that emerged in relation to receptionists, this could provide an area of initial focus.

They never listen; never ever listen. Basic communication skills are not taught at the induction (nurses, reception staff etc)—*COPD.*

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

EMOTIONAL AWARENESS

- Many sources of dissatisfaction relate to a perceived lack of compassion or ‘bedside manner’ on the part of clinical staff.
- Training to raise awareness of this perception and encourage/enable clinical staff to embed consideration for emotional needs and states could represent a cost-effective method of increasing patient satisfaction.

The nurse askes me lots of questions but she never asks if I am frightened or not – I am always frightened in hospital.

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

THIRD-SECTOR NETWORK BUILDING

- Third-sector support services were were a strong source of patient satisfaction.
- In contrast, the CCG was seen as the organisation responsibility for stripping back these services.
- By raising awareness of the connection between the CCG and third sector, the CCG will become more positive as closely associated with the positive impact that it has on patient lives.
- Consider CCG role as a champion of third sector—building, coordinating and promoting access to services.

I want to know how they are going to fund the third sector. That’s really the support we need.

Without [support service coordinator] I just don’t know where I’d be. I owe her everything.

NEMS

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

EXTEND OUTREACH TO IMPROVE EARLY DETECTION

- Whilst outreach maybe costly, a number of participants pointed out that it serves a dual purpose.
- Not only does it increase the likelihood of detecting hidden conditions such as COPD, but communicates the CCG's pro-active approach to detection and their commitment to communities.
- If activity was focussed on high-profile, high-footfall events and venues, the impact could be maximised.

We need to use health melas and things like that for PR purposes. Get people out there in front of everyone with equipment.

I was diagnosed when someone at the Health Mela told me I had a lung age of 113!

INCREASING SATISFACTION

IMPROVING SERVICE QUALITY

PRIORITY APPOINTMENTS FOR SPECIFIC CONDITIONS

- Some specific conditions are acutely sensitive to prolonged waiting.
- This was most pronounced for mental health, dementia and those with learning difficulties.
- A system that allows priority appointments for these patients, in recognition of the particular nature of their condition, would increase satisfaction with each episode
- This demonstration of understanding and responsiveness that it represents would also contribute directly to overall satisfaction.

I'd like dementia sufferers to be treated like diabetics. If they come in with a cut and they're diabetic, they're like quick, rush them through. They should have a similar thing for dementia suffers. So you're not stuck in this queue.

NEMS

INCREASING SATISFACTION

MANAGING EXPECTATIONS

EXTEND PATIENT ENGAGEMENT

- The engagement process itself has a positive effect on satisfaction.
- It yields insights that allow for more effective service re-design and demonstrates consideration for marginalised groups.
- The more qualitative formats (focus groups, co-creation workshops) engage patients with the reality of change within the NHS and promote a more reasoned opinion.
- As such, patient engagement and research can be used to both manage expectation and improve service.

There should be more of these meetings. I know loads of people who would be interested in taking part—*MH*

INCREASING SATISFACTION

MANAGING EXPECTATIONS

PRE-EMPTIVE COMMUNICATION

- Patient satisfaction is largely the result of an emotional reaction to a specific experience.
- As such, upfront, pre-emptive communication about a change in service will mentally prepare patients and manage expectations, resulting in less frustration and dissatisfaction.

If a change needs to happen because of financial constraints, then at least tell us that we can't be admitted today or let us know in advance that something is changing. We're not daft, I'd appreciate that.

They'd stop grumbling [if they knew what was going on].

Not only telling you, but telling what impact there is on you from those changes.

INCREASING SATISFACTION

MANAGING EXPECTATIONS

SOCIAL MARKETING TO REDUCE STIGMA AND INCREASE PUBLIC AWARENESS

- A number of patient groups felt overlooked by the NHS and stigmatised by staff and the general public.
- This applied most particularly to mental health, diabetes and ME.
- Public awareness activity aimed at these stigmas would increase sensitivity amongst staff.
- It would also send a visible signal that the CCG is representing those conditions and serving an advocate role.

They need to be doing more [to combat stigma.] They all think we're stupid—and that's the staff as well as everyone else.

INCREASING SATISFACTION

MANAGING EXPECTATIONS

PERCEIVED FAIRNESS

- Tolerance for change that negatively effects services is reduced when patients perceive a lack of fairness in the allocation of resources.
- Expectations could be managed more effectively if these perceptions were addressed / corrected through targeted, patient-centred communications.

I'm having my [diabetes] services cut back and my friend's daughter is having a boob job on the NHS!"

I've been paying into the NHS all my life and now I need it…

Can't keep spending money on wars and letting people into the country and stripping all the money out of the NHS.

There's people that have come to this country that have never done a day's work.

INCREASING SATISFACTION

MANAGING EXPECTATIONS

AWARENESS OF WIDER CONTEXT

- Several participants had experienced healthcare outside of the UK.
- Their perspectives suggest that expectations could be managed more effectively if patients had more knowledge of this international context as a comparison.

A lot of people moan about the NHS, but I've seen what it's like in Israel and America. People here don't realise how good they have it.

INCREASING SATISFACTION

MANAGING EXPECTATIONS

AWARENESS OF VALUE OF NHS

- Increasing awareness of the cost of NHS services could help manage expectations and reduce cultures of entitlement.
- There was acknowledgement that the NHS is taken for granted as a free service: if it doesn't cost anything then its true value isn't felt.
- An understanding of the cost of NHS treatment helps bring service delivery within the bounds of expectation.
- A number suggested that the cost of all treatments and consultations should be publicised and introducing charges for DNAs was generally supported.

I think if people knew how much things cost [they'd be more appreciative]. If we'd have gone privately with my wife's knee it would have cost £12,000.

Even though we aren't paying for it, if we knew how much it cost it would make us value it more.

They charge for the dentist. It's just gone up—£50. And yes you might think £50!?, but what does it teach you? It teaches you to clean your teeth better!

They should charge those that don't show up. It's scandalous.

INCREASING SATISFACTION

AT A GLANCE: COMMON PRIORITES

DIS/SATISFACTION	ACTIONS	
Individual needs	Third-sector awareness packs	Social marketing
No point of contact	Condition/characteristic specific access points. Email/phone/social media.	Third-sector network building
Communicating changes	Segment specific, tailored communications	Third-sector network building
Respect & Dignity	Communication skills	Emotional awareness
Receptionists	Communication skills	
Continuity of Care	Internal systems	
Coordination of Care	Internal systems	
Community support	Third-sector network building	
Signposting	Third-sector network building	
Waiting Times	Internal systems	
Perceived Waste	Bring back schemes	

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INCREASING SATISFACTION

AT A GLANCE: BURNING ISSUES

PROFILE	DIS/SATISFACTION	ACTIONS	
Mental Health	Waiting times	Priority appointments	
Mental Health	Second-class patients	Social marketing	Third-sector awareness packs
COPD	Being listened to	Communication skills	Emotional awareness
COPD	Early diagnosis	Outreach	Social marketing
Diabetes	Health inequalities & patient empowerment	Outreach	Social marketing
Diabetes	Stigma	Social marketing	Third-sector awareness packs
Dementia	Carer Support	Third-sector network building	
Dementia	Service understanding	Third-sector awareness packs	
BME	Cultural sensitivity	Third-sector awareness packs	
BME	Cleanliness	Communication	
CYP	Respect & dignity	Third-sector awareness packs	Social marketing
CYP	Positivity	Activate as ambassadores	
LGBT	Respect & dignity	Third-sector awareness packs	Social marketing
LGBT	GP Awareness	Third-sector awareness packs	
LD	Preparation & planning	Third-sector awareness packs	Communication skills
LD	Practicalities	Priority appointments	
ME / CFS	Recognition	Social marketing	
ME / CFS	Treatment	Third-sector awareness packs	

INCREASING SATISFACTION

IDEAS WALL

Less agency staff!

Charge for failure to keep an appointment

Specialised services: centres of excellence.

GP clinic for COPD

One-stop-shop for multiple conditions

Nurses' training for diabetes.

Annual check for inter-related conditions.

Disabled toilets need to have enough room for carer.

Helping people with low social skills

Stress help for carers.

Emergency access to expert help.

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KEY

PD	Physical Disability
BME	Black / Ethnic Minority
COPD	Chronic Obstructive Pulmonary Disease
MH	Mental Health
LGBT	Lesbian, Gay, Bisexual or Transgender
ME	Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)
LD	Learning Difficulties