healthwatch Birmingham

Young people's experiences of patient centred primary care in Birmingham

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Young people's experiences of patient centred primary care in Birmingham

Foreword

Welcome to *Young people's perception of patient centred primary care in Birmingham*, a report of an investigation by Healthwatch Birmingham into the level of patient centred care experienced by young people in the city.

This report marks a significant milestone for Healthwatch Birmingham because it is the first major investigation we have conducted since developing a new strategic approach, which focuses on using public, patient, service user and carer experience of using services to identify avoidable health inequity arising from the way services are arranged and delivered.

Our investigation is also important because it is the first time we have been able to listen to the real experiences of people using health and care services in Birmingham from *every* district in Birmingham - in this case the city's children and young people - and publish our findings in a report. This enables us to raise issues which are of mutual relevance and importance to Birmingham's Clinical Commissioning Groups (CCGs). This strategy has received welcome support from all three CCGs.

This will provide a real opportunity for people in Birmingham to help shape and influence the outcomes of our research and make sure that health services are improved in a way that is important to them.

This report reveals indicators of avoidable health inequity which could have lasting implications for the way young people use health services for the rest of their lives. It provides a glimpse into children and young people's actual experience of using primary care services and offers an insight into the ways that services need to be improved.

We will be working with all three CCGs to understand their timelines and progress against our recommendations and when Healthwatch Birmingham should expect to see differences for children and young people accessing primary care in Birmingham.

We would like to thank all of the young people that agreed to be interviewed, and the organisations that helped us to recruit respondents, including the South and City College Birmingham and the Birmingham Safeguarding Children Board, and the Royal Orthopaedic Hospital NHS Foundation Trust.

Candy Perry
Interim Chief Officer, Healthwatch Birmingham

Executive Summary

What we did:

Between October and December 2015 Healthwatch Birmingham staff and volunteers asked more than 300 young people (aged 16-25 years) about their experiences of patient centred care in general practice consultations and about their use of health services.

Our findings:

1. The level of patient centred care experienced by young people in Birmingham is not consistent or good enough:
   - One in five young people visiting their Birmingham medical practice in the last 12 months rated the level of patient centred care they experienced as either 'poor' or 'fair.'
   - When asked: 'How good was the receptionist at making you feel at ease?' nearly one in three (30%) answered 'poor' or 'fair.'
   - When asked: 'How good was the receptionist at showing care and compassion?' more than four in ten (41%) responded 'poor' or 'fair.'

2. Many young people experience avoidable barriers to attending their general practice:
   - Nearly one in three (29%) respondents felt embarrassed about a health problem.
   - A quarter (25%) said they found it difficult to obtain an appointment.
   - One in five (20%) were put off by having to disclose a health concern to the receptionist.

3. Some young people are 'voting with their feet' and going elsewhere.
   A survey of young people who were registered with a Birmingham GP but who had not attended a consultation in the last year revealed that when they had a health concern:
   - Nearly a quarter (24%) went to a walk in centre.
   - Around one in 6 (15%) attended A&E.
   - One in five sought advice in the pharmacy.

Recommendations:

Birmingham CCGs should improve the level of patient centred care experienced by young people in all the services they commission.

They could do this by:

- Listening to the experiences of young people expressed in this report and acting on them by encouraging general practices to provide high quality care to this age group.
- Encouraging young people to become involved in Patient Participation Groups.
- Collating the views of young people and using them to improve patient centred care.

- Encouraging all providers they commission to upload the Healthwatch Birmingham online feedback portal on their website and make a note of any feedback left by young people.
- Auditing the level of shared decision-making between young patients and clinicians in general practice.

Responses:

We received responses from all three of the Birmingham clinical commissioning groups (CCGs), outlining how they plan to continue to improve the level of patient centred care experienced by young people in all the services they commission. These responses are published in full on pages 15-21.

We are encouraged by these responses, and look forward to increasingly seeing more patient and public involvement, insight and experience being used by CCGs, now and in the future, to prevent their services causing avoidable health inequity.

Introduction

This is a report of an investigation into the level of patient centred care[1] experienced by young people (aged 16-25 years old) in primary care services in Birmingham. It discusses how these experiences might impact on their use of health services in future.

Its purpose is to highlight to Birmingham's three CCGs how they could use the views of these service users to improve services for young people.

The research was undertaken because we were concerned about some of the negative feedback we have heard from service users.

A statutory function of Healthwatch Birmingham (HWB) is to listen to the views of the public regarding their experiences of health and social services[2]. We are the public's champion, bringing these experiences to the attention of providers and commissioners.

One of the ways that we listen to Birmingham's patients, public, service users and carers is through our feedback portal; the 'widget'. This can be accessed via the Healthwatch Birmingham website and increasingly through provider's websites across the City.

Feedback via this portal often focuses on the level of patient centred care.

Examples include:

> *"A lot of doctors, around 5 or 6, all but 2 didn't seem to listen to what I was saying. One just fobbed me off and made out as though I was making it up"*
> *"Awful, uncaring, rude"*
> *"GPs are always good for me and listen to me"*
> *"Always there for you"*

We met with members of the public who reside in Birmingham to discuss if this negative feedback warranted further investigation. They confirmed that it did and told us that they were particularly interested to find out what was the level of patient centred care experienced by the young people of our city. We therefore went ahead with this investigation.

Why it is important for young people in Birmingham to receive patient centred care

The focus on young people in this survey is warranted by the relatively high numbers of young people living in Birmingham; 14.9% of the population are aged 16 to 24 years, compared to the national average of 11.4% (Office for National Statistics, 2014b).

In addition Birmingham has some of the highest levels of deprivation in the country; 40% of Birmingham's population live in areas described as the most deprived 10% in England (Birmingham City Council, 2013). Social and economic inequities are associated with poorer health outcomes (NICE, 2012), as is the perceived quality of care during consultations (Kelley, Kraft-Todd, Schapira, Kossowsky, & Riess, 2014). Conversely, the level of practitioner empathy has a positive effect on enablement (patient empowerment)

(Mercer, Jani, Maxwell, Wong, & Watt, 2012) and improves patient outcomes (Derksen, Bensing, & Lagro-Janssen, 2013).

For consultations to be truly patient-centred, health and social services need to be designed around the needs of their users, including young people. Young people's views therefore need to be listened to. NHS England guidance in the Local Transformation Plans for Children and Young People's Mental Health and Wellbeing (NHS England, 2015b) states that children and young people want to have the opportunity to shape the services they receive.

This involvement is also demanded by young people themselves in Birmingham. At the January 2016 meeting of the Birmingham Health and Wellbeing Board, the Birmingham Public Health Youth Panel young people presented a video (Birmingham Public Health Youth Panel, 2016) in which young people asked that their views be heard.

Sexual health and young people in Birmingham

Public Health England reports that there are higher rates of acute sexually transmitted infections (STIs) in Birmingham, 37.7 per 1,000 population, compared to the national average of 34.4 (Public Health England, 2016). Also the rate of sexually transmitted infections in 15-24 year olds is much higher than in all other age groups (Public Health England, 2014).

The high level of STI's in Birmingham indicates that health services are not meeting the needs of young people who are sexually active. One reason may be that young people may not feel comfortable discussing sexual health with general practice health professionals. In a survey of 306 people by Haringey CCG, 43% of respondents said that they felt the 'compulsory involvement' of their parents in GP consultations hindered their ability to discuss and address their health needs and concerns (Haringey CCG, 2014). As one respondent stated: '*There is no way I would tell my doctor that I am sexually active. I would be too scared that they would tell my mum.*' Sexual health could be improved by de-stigmatising asking for advice (Public Health England, 2015).

Mental health and young people in Birmingham

Ninety percent of adults with mental health problems are supported in primary care. Half of these problems have been established by the age of 14, a figure which rises to 75% by the age of 24 (Independent Mental Health Task force, 2015). General practice clearly plays an important role in supporting young people with mental health problems.

However, 50% of young people aged 16-25 in Brighton and Hove, responding to a survey, said they would not feel comfortable talking to their GP about emotional or mental health issues (Right Here Brighton and Hove, 2009).

Similarly Healthwatch Essex found in their 'YEAH! Project' that people often felt that GPs did not understand mental health issues in young people, or treat them seriously. This made them feel their health issues were trivial and discouraged them from seeking the help they needed (Healthwatch Essex, 2015).

These findings mirror a Birmingham based study of delayed help seeking by young people with first episode psychosis. This study found that contact with GPs was generally positive, but was hindered by poor communication and lack of engagement (Connor et al., 2014)

It may be that some GPs feel ill-equipped and inadequately prepared to address adolescent emotional distress (Roberts, Crosland, & Fulton, 2013). This is of concern because rapport between a young person and their GP is an important factor in the person's willingness to discuss general and mental health concerns (Churchill et al., 2000).

The ability of GPs to communicate well with young people is important given that they have a key role in addressing youth mental health (Schaffalitzky et al., 2015). Good rapport is associated with better detection rates of youth mental health problems (Haller, Sanci, Sawyer, & Patton, 2009), and 20.8% of adults aged 16-24 experience symptoms of anxiety or depression (Office for National Statistics, 2014a).

The Five Year Forward View for Mental Health (Independent Mental Health Task force, 2015) identified young people as a priority group for mental health promotion and prevention, stating that early intervention is vital, and that significant inequalities in access should be addressed.

However, a review by the Children and Young People's Mental Health Coalition of how well children and young people's mental health is being prioritised in the current commissioning landscape, reported that the needs of young people have been largely overlooked in joint strategic needs assessments (Oliva & Lavis, 2013). That review recommended that the needs of young people, particularly those who are vulnerable, should be supported by the Health and Wellbeing Board and included in the joint strategic needs assessment (JSNA) and the joint health and wellbeing strategy[1].

Having established a wider more significant need to investigate, the way we approached the investigation is outlined in the next section.

[1] The JSNA is the duty of the council and clinical commissioning groups to prepare through the health and wellbeing board (Birmingham Health & Wellbeing Board, 2014).

How we approached the investigation

Between October and December 2015 Healthwatch Birmingham staff and volunteers asked young people (aged 16-25 years) about their experience and views of patient centred care experienced in general practice consultations, and about their use of health services. The demographic characteristics of our sample of young people can be seen in Appendix One.

All ten Birmingham districts were represented.

- **63%** of respondents were within Birmingham Cross City CCG footprint.
- **19%** of respondents were within the Sandwell and West Birmingham CCG footprint.
- **18%** of respondents were within the South Central CCG footprint.

We asked 146 respondents who were registered with a Birmingham GP and had attended a consultation in the last year about their perception of patient centred care. If they had experienced additional health concerns in the past year, which they had not consulted a general practice health professional about, they were asked about any barriers which prevented them attending a general practice consultation. This group formed 48% of respondents.

Although respondents who had recently attended their general practice were our target group, we also recorded information from three more groups of respondents who did not meet the above criteria:

1. Those who were registered with a Birmingham GP but had not attended a consultation in the last year (n=33, 11%).
2. Those who were not registered with a Birmingham GP although they lived in Birmingham (n=36, 12%[2]).
3. Those who did not work or reside in Birmingham (n=89, 29%).

These three groups were asked about barriers to attendance. We also explored 'failure demand' [3] (Seddons, 2008) by ascertaining if these young people had decided to use an alternative service: pharmacist, walk-in centre, Accident and Emergency or NHS 111.

Full details of the survey methodology can be found in Appendix Two.

[2] The majority of these respondents that were not registered with a Birmingham GP were students.
[3] Failure demand is created by a failure to do something or do something properly the first time round, leading to patient seeking care from another part of the health and system such as A&E.

What we found

1. The level of patient centred care experienced by young people in Birmingham is not consistent or good enough

We asked the 146 young people who had visited their Birmingham medical practice in the last 12 months about the level of empathetic patient-centred care they felt they had experienced.

Poor or Fair Care

One in 5 of our sample felt that the level of patient-centred care they experienced was either 'poor' or 'fair'. Responses to individual questions can be seen in Figure 1.

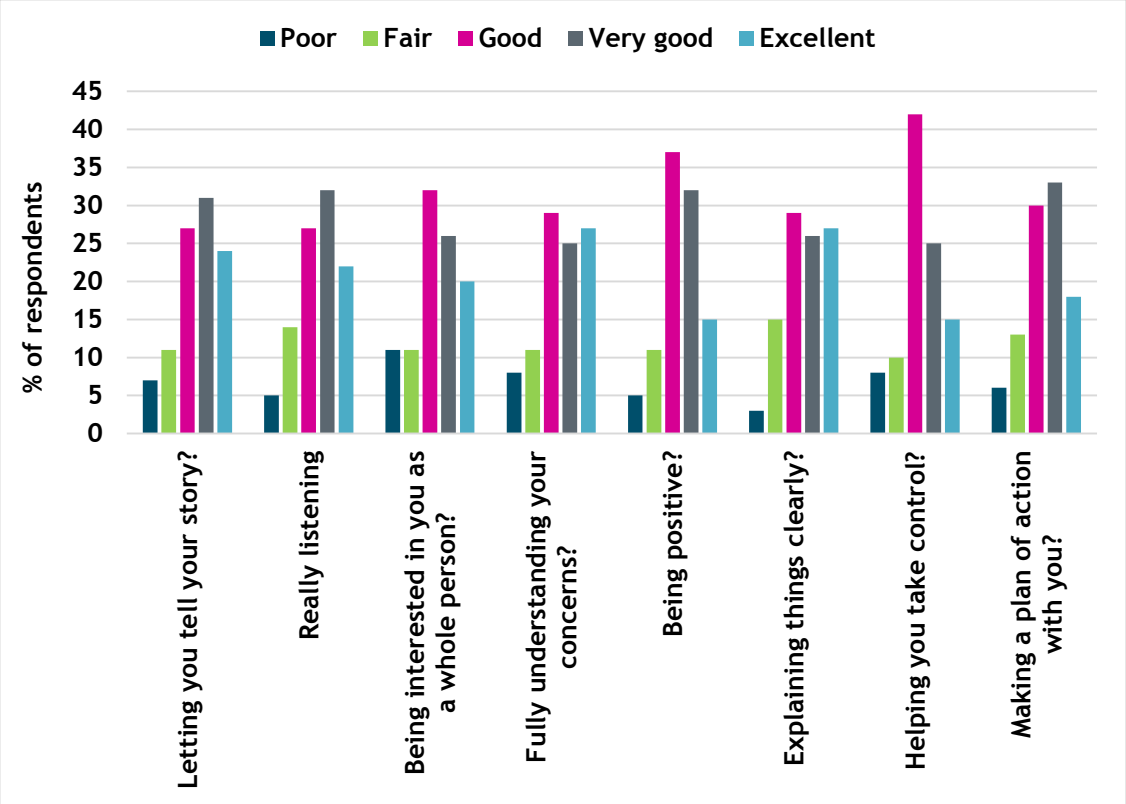

Fig 1. Young people's perceptions of empathic patient-centred care by care practitioners.

These ratings were given by young people who had consultations with the following types of health professionals:

- 76% last had a consultation with a general practitioner
- 17% with a nurse
- 1% a health care assistant
- 4% could not remember the type of practitioner
- 1% did not complete this question.

Young people's perception of general practice receptionists

Young people rated the patient centred care they received from general practice receptionists lower than the level they received from care practitioners.

When asked: 'How good was the receptionist at making you feel at ease?'
30% rated this as either 'poor' or 'fair'.

When asked: 'How good was the receptionist at showing care and compassion?'
41% answered 'poor' or 'fair'.

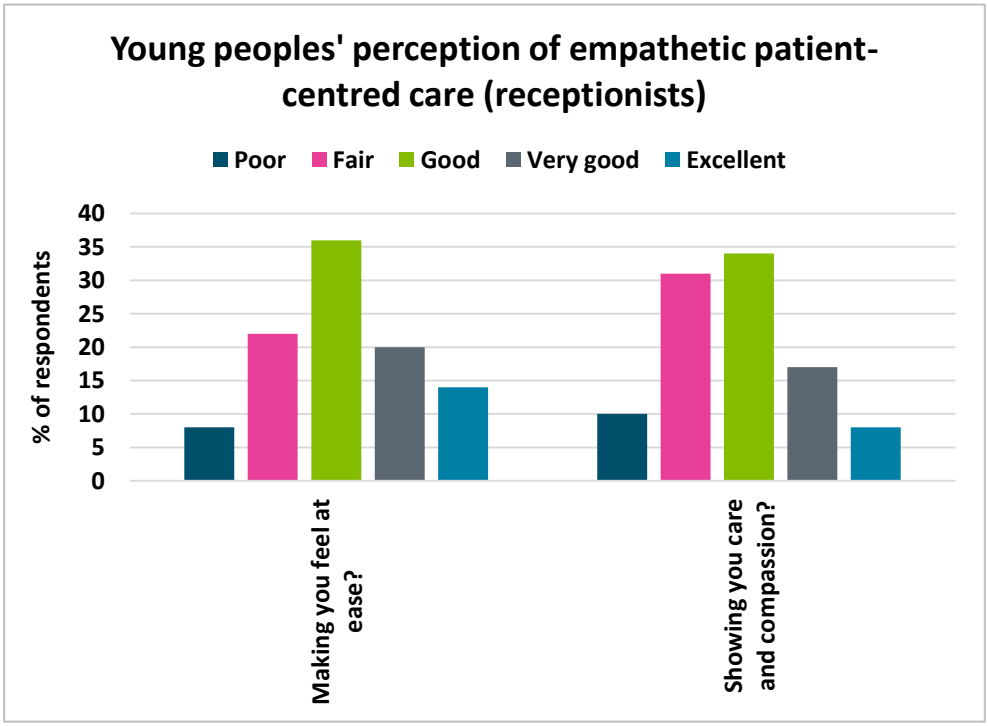

Fig 2: Young people's perception of empathetic patient-centred care (receptionists)

A 2013 CCG report states that 29% of patients in Birmingham were concerned about being overheard at the GP reception desk (Birmingham Cross City CCG;, Birmingham South Central CCG, & Birmingham City Council, n.d.). However, in a national patient survey of general practice 97% of respondents said that the receptionists at their GP surgery were helpful (NHS England, 2015a). These data regarding receptionists need further investigation.

2. Many young people in Birmingham experience avoidable barriers to attending their general practice

We asked 193 young people about deterrents to visiting a medical practice.

This subsample included all interviewees, except those that reported they had seen their GP in the last 12 months but had had a health condition they had not visited GP about.

The most frequently cited deterrents were embarrassment about a health problem (29% of all respondents who were asked this question), difficulty obtaining an appointment (25%) and having to disclose the health concern to the receptionist (20%). Further information can be seen in table 1.

Table 1 Deterrents to attending a general practice consultation reported by young people

	Registered with a Birmingham medical centre		Not registered with a Birmingham medical centre		Total of sample that answered this question (N= 193)
	Attended an appointment in last 12 months but had had health concerns in the last year for which they did not visit their medical practice (N=35)	Not attended an appointment in last 12 months (N=33)	Lives in Birmingham but not registered with a Birmingham GP (N=36)	Does not live in Birmingham and not registered with a Birmingham GP (N=89)	
Embarrassment about a health problem	9 (26%)	12 (36%)	6 (17%)	29 (33%)	56 (29%)
Difficult to obtain an appointment	7 (20%)	11 (33%)	10 (28%)	19 (21%)	49 (25%)
Having to disclose the health concern to the receptionist	4 (11%)	9 (27%)	3 (8%)	22 (25%)	38 (20%)
Not being listened to	2 (9%)	7 (21%)	5 (14%)	20 (22%)	34 (18%)
Concerns about lack of confidentiality	2 (6%)	4 (12%)	3 (8%)	25 (28%)	34 (18%)
Feeling a lack of respect by the staff	2 (6%)	6 (18%)	1 (3%)	23 (26%)	32 (17%)
Uncertainty about which part of the health service to seek help from	3 (9%)	5 (15%)	7 (19%)	15 (17%)	30 (16%)

Previous research indicates that adolescent attitudes may influence attendance at general practice (Ferrin, Gledhill, Kramer, & Elena Garralda, 2009). Embarrassment is known to be

a deterrent in attending consultations (Öztürk, Fleer, Hoekstra, & Hoekstra-Weebers, 2015), particularly among girls with sensitive issues such as contraception or gynaecological problems (Churchill et al., 2000). The problem of accessing general practice consultations is well known, and patient satisfaction is decreasing (NHS England, 2015a). However, it may not be as highly associated with good patient experience as the communication skills of the clinician or the helpfulness of the receptionists (Paddison et al., 2015).

Our data suggest that factors such as being embarrassed about a health problem play a role in some young people in Birmingham not attending their general practice. For example, **36%** of young people who had not attended a consultation at their general practice in the last year said they were deterred by embarrassment about a health problem, and **26%** of young people said they had had a health concern in the last year for which they did not visit their medical practice.

3. Some young people are 'voting with their feet' and going elsewhere in Birmingham.

A high percentage of our respondents who had not visited their general practice are seeking treatment elsewhere. Of those young people who were registered with a Birmingham GP, and had not visited them in the last year (N=33), 24% had attended a walk in centre and 15% had attended A&E. Further information can be found in Figure 3.

This behaviour could affect the way young people consume primary care and the health outcomes they experience.

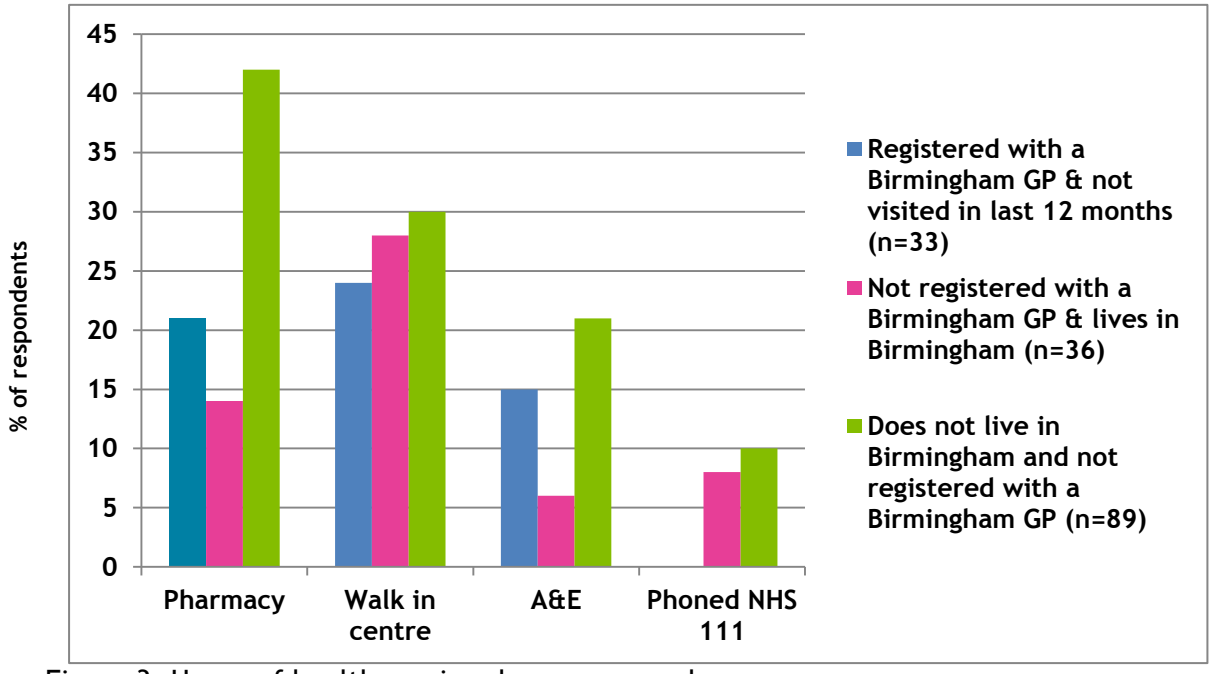

Figure 3. Usage of health services by young people

What needs to change?

Recommendations

We called upon the three Birmingham CCGs to:

1. Inform Healthwatch Birmingham how they plan to improve the level of patient centred care experienced by young people throughout the services they commission.

   There is a growing body of evidence that patient centred care can lead to a reduced demand for services, such as A&E, and therefore support the sustainability of the NHS (RCGP, 2014; Wood, Finnis, Khan, & Ejbye, 2016) . Unfortunately, there is a recognition that person centred care is not yet happening and has a long way to go (Coleman, 2015). A discussion of the barriers to patient-centred care is provided in Appendix three.

   With delegated primary care commissioning CCGs are accountable to NHS England for quality and must take action to assure themselves, through carrots or levers, that general practices are providing high quality care to patients.
   We are interested to know:
   - How CCGs plan to listen to the experiences of young people, understand them and act on the data?
   - How are CCGs encouraging the involvement of young people in Patient Participation Groups?
   - How are CCGs going to collate the views of young people?
   - How are these views going to be used to improve patient centred care?

2. Encourage all providers they commission to upload the Healthwatch Birmingham online feedback portal on to their website. Healthwatch Birmingham have made our online feedback portal available free of charge for all Care Quality Commission registered providers to collect feedback data via their websites. This will increase the availability of feedback routes in the city and provide a consistent, independent, integrated approach to collecting experience data.

3. Share with us their progress of auditing[4] the level of shared decision making (and other important aspects of patient centred care) between patients and clinicians in general practice, including how these data are being used?

4. Use the HWB Quality Standard and Assurance Framework in their audits of Patient and Public Involvement, and use it to prevent avoidable health inequity.

[4] The RCGP inquiry into patient care in the 21st Century recommended that CCGs and general practices audit the level of shared decision making. Page 61 http://bit.ly/11QweCm

Response from Birmingham CCGs

We received responses from three of the Birmingham CCGs, inserted here in full. We will follow up these responses with ongoing discussions to work together to assure good PPI across the City.

NHS
Birmingham CrossCity
Clinical Commissioning Group

NHS Birmingham CrossCity Clinical Commissioning Group (CCG) response

NHS Birmingham CrossCity CCG welcomes this report as a very useful insight into the experiences of young people in our city. Whilst it highlights some key areas for improvement, we also welcome the positive experiences that many young people have had whilst accessing health services in Birmingham.

At Birmingham CrossCity CCG, we have a focus on bespoke and targeted engagement techniques, on a project-by-project basis, based on an equality impact analyses. This is to absolutely ensure that the people most affected by any decision we make, are at the heart of it. This includes considering the age of our patients, as one of the nine protected characteristics, under the Equality Act 2010.

In addition, we encourage our member practices to always ensure that they value and listen to feedback, in order to ensure that services are responsive to the needs of their patients.

We look forward to continuing to develop our relationship and continuing to work closely with Healthwatch Birmingham, to ensure that we are fully accountable to the people of Birmingham; we are committed to ensuring high-quality and local care for our patients in the city.

Our responses to the specific recommendations in the reports are:

How we plan to listen to the experiences of young people, understand them and act on the data
We have a number of ways in which we engage with the local people. The foundations of our engagement are Patient Participation Groups (PPGs) and our People's Health Panel. The People's Health Panel has 3000 members, and 26.9% of members are aged 16-24. This is broadly representative, in comparison to the population.

The People's Health Panel is used as a two-way communications and engagement tool. The main channels being newsletters, surveys, workshops, focus groups and events. The newsletter is achieving an open rate of 38.1%, against an industry standard of circa 20%. The newsletter is also available in audio, with a signed version planned for spring 2016.

In addition, we have been working hard to bring engagement and equality and diversity closer together. We recognise the value of incorporating diversity considerations within our engagement workstreams, and this ensures a thorough approach to engaging our diverse population in our work. We have developed some important partnerships with several key organisations across the city.

How we encourage the involvement of young people in Patient Participation Groups
PPGs are practice based and therefore encouraging involvement from any person or group would ultimately be the responsibility of the practice staff and the PPG chair.

However, to support our practices in developing their PPGs, in summer 2016 we will be rolling out a PPG toolkit which will include resources for recruiting new members to PPGs that historically may have been less engaged. These resources will include items such as best practice ideas, techniques and tools, as well as tangible resources such as promotional postcards and posters for the practice.

We will also be supporting this through communications activity, via the CCG's well-established communication channels that we know young people use e.g. Facebook and Twitter, and also by engaging with our partners in the city who already have well-established relationships with local young people.

How we collate the views of young people to improve patient care
We use a variety of methods to collate the views of our patients. The information collected from any of our engagement is collated together to form a report, which be presented to relevant committees and boards, and where appropriate, the Governing Body.

It is crucial to have clear processes for sharing this rich intelligence and information, to ensure it feeds into the continuous improvement of the quality of care that we commission and the decisions that the CCG makes. Not only is this essential under our statutory duties as a CCG, but effective engagement is also something that we are working towards becoming an exemplar organisation for. We also undertake a continuous process of reviewing and evaluating our activities, to ensure that they are working effectively and are always based on best practice.

How we will encourage providers to upload the online feedback portal and record any feedback left by young people
We will take regular opportunities, through our well-established communications and engagement relationships and networks with our providers, to positively promote the benefits of the online feedback portal to them.

NHS
Birmingham South Central
Clinical Commissioning Group

NHS Birmingham South Central Clinical Commissioning Group (CCG) response

We would like to thank you and the team for the work that has gone in to producing this report and for the opportunities it presents to help improve our engagement with young people in the city and to develop more personalised care.

Below is our response to the specific recommendations highlighted.

1. Listening to the experiences of young people expressed in this report and acting on them by encouraging general practices to provide high quality care to this age group.

- We will cascade the report and its findings to our six networks and invite Healthwatch to outline its recommendations at a future Member Council and Governing Body.
- Host a focused event to explore the practical next steps for young people in relation to the report's findings (with linked 'snapshot' focus groups to sense check our approach).
- Host joint Ideas Café drop-in sessions with Healthwatch (in appropriate venues) to feedback how the recommendations are being taken forward.

2. Encouraging young people to become involved in Patient Participation Groups (PPGs).

- Ask our Citizens Group to consider the report and relate it to their future projects list.
- Invite Healthwatch Birmingham & Healthwatch Worcestershire to the next PPG Forum meeting and involve them in our planned event for PPG Awareness Week 2016 at Newman University in June.
- Host a follow up to our recent Question & Answer Panel (with New Style Radio's Charmaine Burton) at Bournville College exploring the themes raised.
- Work with Healthwatch to improve digital signage and how useful information is provided within our practices.

3. Collating the views of young people and using them to improve patient centred care.

- Review our current feedback mechanisms and support Healthwatch in its role to collate and co-ordinate views, feedback and comment across the local health economy.
- Host a roundtable podcast/radio debate with partner agencies and young people from across the city to openly discuss the issues identified and how they can be resolved.
- Support Healthwatch to ensure a focus beyond primary care and to build on research from other areas highlighting poor access in mental health services and a reluctance to get advice from a GP.
- Promote Forward Thinking Birmingham's new PAUSE city centre drop-in service which aims to make services more accessible, in parallel with improved on-line resources and a programme of up skilling for local GP's to enhance their support offer for young people in the city.

- Link our work through a schools based pilot and the Head Start approach to improve prevention and to pick up problems as early as possible, thus reducing more serious mental health issues.

4. Encouraging all providers they commission to upload the Healthwatch Birmingham online feedback portal on their website and make a note of any feedback left by young people.

- We have already uploaded the widget to BSC CCG's website: http://bhamsouthcentralccg.nhs.uk/get-involved/healthwatch-birmingham
- We are identifying up to five GP surgeries from across our area to trial using the widget on their practice website.
- Recognise the feedback portal as a strand of activity within the CCG's Partnerships Framework and recommend its use to partners, providers and practices.
- Invite those that participated in the research to a 'Hack' event to help us develop our newly refreshed website.
- For 2015/16, the Primary Care Committee has agreed that GP practices will qualify for the Quality & Innovation Reward Scheme where they agree to adopt the St Basil's Charter for young people in care. The Charter was endorsed by BSC CCG's Governing Body in 2013 and we have actively encouraged its adoption amongst our practices.

5. Auditing the level of shared decision-making between young patients and clinicians in general practice.

- We will link these findings to the outcomes of our recent Governance Review, which includes a consideration of the focus and style of our meetings, their timings and location, as well as the accessibility of the meeting agenda.
- We will identify opportunities for greater public input in other key decision-making forums, such as our Primary Care Committee.

We see these report findings as a positive way to further embed our partnerships approach which is based on three key engagement principles:

Our activity must be accessible - How do I get to it?

- We must ensure that citizens can understand, explore and identify with our services openly.
- This means an approach that is social, informal, yet structured.

Our activity must be relevant - How will it affect me?

- We must clearly relate our services to the day to day lives of our citizens.
- This means an approach that relates to individual context and lead by our membership and local networks.

Our activity must be action-orientated - What difference does it make?

- We must build dialogue and relationships through which we are able to demonstrate how we have responded in a timely way and be honest in our communication of change.
- This means an approach that operates in real-time, demonstrates an open capture of feedback and promotes dialogue through a variety of means.

These principles support the Five Years Forward view which sees the NHS as a social movement for change and we are enthused by the potential this review presents.

NHS
Sandwell and West Birmingham
Clinical Commissioning Group

Sandwell and West Birmingham Clinical Commissioning Group (CCG) response

Sandwell and West Birmingham CCG welcome the findings of the Healthwatch report about the experience of young people when accessing general practice.

Since taking on responsibility for primary care services the CCG has been looking at GP access in general and at the experience of young people in particular. The CCG is aware that it will need to encourage young people to join participation groups and is looking to make stronger links with schools and colleges to enable their needs to be listened to.

Our listening exercise undertaken last autumn has been included in our Primary Care strategy. Primary care services are the foundation of the local health system. Over 90% of all patient contact with the health service happens in primary care with general practitioners (GPs) being the key gatekeepers to hospital and other specialist healthcare services. We recognise that to deliver a sustainable health and social care system, we must have a strong primary care service. In particular, we know we need to develop primary care services that are:

- Stable
- High quality
- Accessible
- Focused on prevention- helping patients to stay healthy for longer.

As a clinically-led membership organisation, we are uniquely placed to deliver change and improvements in primary care. This strategy aims to build on this opportunity.

We have developed 10 priorities for primary care, which are based on:

- What patients, carers and our local communities have told us about their current primary care experiences and what they want to see changed now and in the future
- What member practices have told us about their key concerns and how these should be addressed now and in the future
- Our wider strategic aims and priorities
- National best practice and guidance.

Our vision for local general practice in 2020

- Accessible, high-quality, comprehensive healthcare services available for all
- An excellent care experience for patients, carers and families
- Patients and carers participating as partners in their care, empowered to make informed decisions
- An expanded, skilled, resilient and adaptable general practice workforce
- Community-based premises for delivering care, teaching, training and research that are fit for the future and are conducive to better health and wellbeing

- Less fragmentation of care through coordination and collaboration across boundaries, supported by joint commissioning arrangements
- Reduced health inequalities and increased community self-sufficiency
- Greater use of information and technology to improve wellbeing, health and care
- Improved understanding and management of inappropriate variability in quality
- More community-led research, development and quality improvement

The CCG already engages with young people in a number of areas for their views, such as child sexual exploitation and will build on these established links.

We will also develop training and customer care for practice staff within the existing training programmes. We need to ensure that we are delivering healthcare that meets young peoples' changing needs wherever and whenever they wish to access it. We will also look at how we incorporate the voice of young people in decisions made about their health through our quality and primary care workstreams.

There are some specific further actions we can take:

1. Listening to the experiences of young people expressed in this report and acting on them by encouraging general practices to provide high quality care to this age group.

- We will cascade the report and its findings to our member practices and invite Healthwatch to outline its recommendations at a future Governing Body.
- We will extend the current training aimed at reception staff to include YP friendly/customer care training. Currently the training offered is focusing on vulnerable groups, so young people could be identified through that process.
- Investigate introducing a YP friendly scheme into primary care (based on the previous "Your Welcome" standards). This is something we could work with local young people and Healthwatch colleagues on.
- We will monitor YP feedback on the Healthwatch portal and listen & react to this.
- The CCG is already investing in technology - SMS, APPS - wifi in all NHS buildings in next few years and will continue to develop use of social media

2. Encouraging young people to become involved in Patient Participation Groups (PPGs).

- We will work with Healthwatch to improve digital signage and how useful information is provided within our practices.
- We are currently in the process of redesigning our PPI Toolkit, so we could widen the tools of engagement around PPG's to be more inclusive of YP e.g. making better use of social media
- We have engaged a trainer who is currently running a programme aimed at effective PPGs and growing patient participation for PMs

3. Collating the views of young people and using them to improve patient centred care.

- We will review our current feedback mechanisms and support Healthwatch in its role to collate and co-ordinate views, feedback and comment across the local health economy.
- We will support Healthwatch to ensure a focus beyond primary care and to build on research from other areas highlighting poor access in mental health services and a reluctance to get advice from a GP.
- We will with our colleagues in the other Birmingham CCG's promote Forward Thinking Birmingham's new PAUSE city centre drop-in service which aims to make services more accessible, in parallel with improved on-line resources and a programme of up skilling for local GP's to enhance their support offer for young people in the city.

4. Encouraging all providers they commission to upload the Healthwatch Birmingham online feedback portal on their website and make a note of any feedback left by young people.

- We will expect our commissioned services to upload the Healthwatch feedback "widget" onto their home web page and work with Healthwatch to distribute promotional materials promoting the feedback tool.
- We will identify GP surgeries from across our area to trial using the "widget" on their practice website.
- We will recognise the feedback portal as a strand of activity within the CCG's Partnerships Framework and recommend its use to partners, providers and practices.
- We have commissioned our Commissioning Support Unit to lead a co-design piece of work with young people (on the back of the work with iMPOWER). We are working with young people across Birmingham in the 18-25 age category to co-design solutions ahead of winter 2016. Part of this will inevitably include primary care. The design and digital team will start working on concepts for the campaign branding and visuals as created by YP

5. Auditing the level of shared decision-making between young patients and clinicians in general practice.

We will link these findings to the all the work to be undertaken with our patient engagement and communication teams over the coming weeks and months.

We thank you for the opportunity to build on existing partnerships and to build on the work for the benefit of Birmingham's young people.

Appendix One: Demographic data tables

Demographic characteristics

	Registered with a GP and had attended an appointment in the previous year (N=146)	Registered with a GP but had not attended an appointment in the previous year (N=33)	Lives in Birmingham but not registered with a GP (n=36)	Comparison group - does not live in Birmingham and not registered with a GP in Birmingham (N= 89)	Total
Gender					
Female	88 (60%)	14 (42%)	15 (42%)	59 (66%)	176 (58%)
Male	56 (38%)	19 (58%)	20 (56%)	28 (31%)	123 (40%)
Prefer not to say	1 (1%)	0 (0%)	1 (3%)	2 (2%)	4 (1%)
Missing	1 (1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Age group					
16-18	60 (41%)	14 (42%)	12 (33%)	36 (40%)	122 (40%)
19-21	45 (31%)	8 (24%)	17 (47%)	25 (28%)	95 (31%)
22-25	41 (28%)	11 (33%)	7 (19%)	28 (31%)	87 (29%)
Resident in Birmingham					
Yes	116 (79%)	22 (66%)	36 (100%)	0 (0%)	174 (57%)
No	30 (21%)	11 (33%)	0 (0%)	89 (100%)	130 (43%)
CCG area of the residents (n=174):					
Cross City	73 (63%)	14 (64%)	21 (58%)	N/A	108 (62%)
South Central	21 (19%)	4 (18%)	10 (28%)	N/A	35 (20%)
Sandwell and West Birmingham	22 (18%)	4 (18%)	5 (14%)	N/A	31 (18%)
Respondent considers themselves a disabled person					
No	131 (90%)	31 (94%)	32 (89%)	86 (97%)	280 (92%)
Yes	9 (6%)	2 (6%)	3 (8%)	2 (2%)	16 (5%)
Prefer not to say	3 (2%)	0 (0%)	1 (3%)	1 (1%)	5 (2%)
Other	2 (1%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)
Blank	1 (1%)	0 (0%)	0 (0%)	0 (0%)	1 (0%)

Demographic characteristics continued.

	Registered with a GP and had attended an appointment in the previous year (N=146)	Registered with a GP but had not attended an appointment in the previous year (N=33)	Lives in Birmingham but not registered with a GP (n=36)	Comparison group (N= 89)	Total
Religion/belief					
Christian	39 (27%)	11 (33%)	9 (25%)	26 (29%)	85 (28%)
No Religion/Belief	26 (18%)	6 (18%)	6 (17%)	19 (21%)	57 (19%)
Atheist	21 (14%)	3 (9%)	6 (17%)	19 (21%)	49 (16%)
Agnostic	20 (14%)	2 (6%)	4 (11%)	13 (15%)	39 (13%)
Muslim	25 (17%)	6 (18%)	5 (14%)	0 (0%)	36 (12%)
Sikh	5 (3%)	1 (3%)	0 (0%)	2 (2%)	8 (3%)
Hindu	1 (1%)	2 (6%)	2 (6%)	3 (3%)	8 (3%)
Buddhist	1 (1%)	0 (0%)	0 (0%)	1 (1%)	2 (1%)
Jewish	0 (0%)	0 (0%)	2 (6%)	0 (0%)	2 (1%)
Rastafarian	1 (1%)	0 (0%)	0 (0%)	1 (1%)	2 (1%)
Prefer not to say	3 (2%)	2 (6%)	2 (6%)	3 (3%)	10 (3%)
Other	0 (0%)	0 (0%)	0 (0%)	2 (2%)	0 (0%)
Blank	4 (3%)	0 (0%)	0 (0%)	0 (0%)	6 (2%)
Ethnicity					
White British	82 (56%)	14 (42%)	20 (56%)	74 (83%)	190 (63%)
Pakistani	14 (10%)	4 (12%)	1 (3%)	0 (0%)	19 (6%)
Indian	9 (6%)	5 (15%)	2 (6%)	5 (6%)	21 (7%)
Black African	8 (5%)	3 (9%)	4 (11%)	2 (2%)	17 (6%)
White other	4 (3%)	0 (0%)	4 (11%)	1 (1%)	9 (3%)
Black Afro-Caribbean	7 (5%)	0 (0%)	0 (0%)	0 (0%)	7 (2%)
Black British	4 (3%)	2 (6%)	0 (0%)	1 (1%)	7 (2%)
Chinese	3 (2%)	2 (6%)	0 (0%)	2 (2%)	7 (2%)
Eastern European	1 (1%)	1 (3%)	2 (6%)	0 (0%)	4 (1%)
Bangladeshi	3 (2%)	0 (0%)	0 (0%)	0 (0%)	3 (1%)
White Irish	2 (1%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)
Somali	1 (1%)	0 (0%)	0 (0%)	0 (0%)	1 (0%)
Dual Heritage	1 (1%)	0 (0%)	0 (0%)	0 (0%)	1 (0%)
Prefer not to say	1 (1%)	0 (0%)	1 (3%)	2 (2%)	4 (1%)
Other	6 (4%)	2 (6%)	2 (6%)	2 (2%)	12 (4%)
Sexual Orientation					
Heterosexual/Straight	129 (88%)	25 (76%)	32 (89%)	77 (87%)	263 (87%)
Bisexual	7 (5%)	5 (15%)	0 (0%)	7 (8%)	19 (6%)
Prefer not to say	7 (5%)	2 (6%)	2 (6%)	2 (2%)	13 (4%)
Gay/Lesbian	2 (1%)	1 (3%)	0 (0%)	3 (3%)	6 (2%)
Other	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Blank	1 (1%)	0 (0%)	2 (6%)	0 (0%)	3 (1%)
Employment status					
Student	101 (69%)	19 (58%)	28 (78%)	55 (62%)	203 (67%)
Employed	31 (21%)	13 (39%)	3 (8%)	28 (31%)	75 (25%)
Out of work	3 (2%)	1 (3%)	3 (8%)	4 (4%)	11 (4%)
Unable to work	8 (5%)	0 (0%)	0 (0%)	1 (1%)	9 (3%)
Mother	1 (1%)	0 (0%)	1 (3%)	0 (0%)	2 (1%)
Self employed	0 (0%)	0 (0%)	1 (3%)	1 (1%)	2 (1%)
Missing	2 (1%)	0 (0%)	0 (0%)	0 (0%)	2 (1%)

Appendix Two: Methods

Respondents

The survey was conducted between October and December 2015. We were keen to get a representative sample of young people in Birmingham[5]. Healthwatch staff and volunteers therefore conducted face to face interviews at a number of locations across the city including:

- The canteen of South and City College Birmingham, Handsworth
- Birmingham City Centre (New Street, Colmore Row and outside of St Martin's Church)
- The queue of a music venue (02 Academy, Horsefair).

We also advertised the survey via social media and via key stakeholders for completion online.

Inclusion criteria to complete the questions regarding care and compassion experienced at the medical practice were that: the respondent was registered with a medical practice in Birmingham, which they had visiting in the previous 12 months, and were aged between 16 and 25 years.

We were also interested in deterrents to attending medical practice consultations and patients' alternative use of NHS services. Questions regarding these topics were asked if the respondent was:

- Registered with a Birmingham medical practice and said that they had had a condition in the last 12 months that they had not consulted a health professional at their medical practice about
- Registered with a Birmingham medical practice but had not attended in the previous 12 months
- Not registered with a Birmingham medical practice and lived in Birmingham
- Neither lived or worked in Birmingham and not registered with a Birmingham medical practice.

Data are provided separately in the results section for these different categories of respondents.

It was assumed that by completing the survey the interviewee had consented to participate in the study. Interviewees were told that all information would be treated as confidential.

Interviewers

The survey was mainly conducted by Healthwatch Birmingham volunteers. These are people that either reside within Birmingham or are a service user of health and social care

[5] We had originally planned to conduct the survey in more locations throughout the city. However, we found that young people rarely wanted to stop to be interviewed. We therefore changed the locations to ones with large amounts of young people; the city centre, in a college, and in the queue of a major music venue. We had hoped that the ability to complete the survey online would result in a more even spread across the three CCG footprints. Future surveys will build on the learning from this survey, and will use our deepening relationships with the third sector, and within the health and social care system to recruit research participants.

within the city and over the age of 18 years. Volunteers and staff attended a training session during which the inclusion/exclusion criteria and purpose of the survey were discussed, attendees were taught how to use the iPad, and their interviewing skills were polished. Interviewers were also consulted about the format and content of the questionnaire, which was revised accordingly.

Questionnaire

The questionnaire was designed in collaboration with a research advisory group of volunteers, which was then piloted with 25 young people (20 online and 5 face to face on Handsworth High Street) and revised.

Consultation and relational empathy

As there was no validated tool that matched the purpose and design of this survey, and Healthwatch Birmingham do not have the resources to develop and validate such a measure, we adapted questions from an existing tool, the Care and Relational Empathy (CARE) Patient Feedback Measure[6]. We fully acknowledge that this measure was not developed for the purpose we used it for and offer these findings as an exploration of the subject matter.

Healthcare Professionals

The CARE Patient Feedback Measures consists of ten questions. Due to a technical problem the data for two of these ten questions were not recorded and could not be included in our analysis. The eight patient feedback questions were asked with regard to consultations with either the GP, Nurse or Healthcare Assistant. These were scored: 'poor'=1, 'fair' = 2, 'good' = 3, 'very good' = 4, and 'excellent'= 5. All eight items were then added, giving a maximum possible score of 40, and a minimum of 8.

Medical Practice Receptionists

Two questions relating to young people's experience of the empathetic patient-centred care of receptionists were asked. The wording of these questions was adapted from the two questions included in the CARE Patient Feedback Measure. They were scored as: 'poor'=1, 'fair' = 2, 'good' = 3, 'very good' = 4, and 'excellent'= 5, and are shown separately in the results tables.

The questionnaire was administered via iPads. This ensured that the correct pathway through the questionnaire was followed, based on answers given to proceeding questions. The digital administration of the questionnaire also ensured that all questions were answered before the respondent could move on to the next page of the questionnaire. This eliminated missing data, although respondents were given the option of 'prefer not to say' for most questions. The use of an iPad also reduced data entry errors as data were automatically downloaded to an Excel spreadsheet for analysis.

[6] http://www.caremeasure.org/

Data analysis

Descriptive statistics were calculated. Comparative statistics between categories of respondents or demographic subgroups were not calculated. This was because the survey was not designed for this purpose, and therefore the number of respondents in subgroups was not sufficiently large to conduct meaningful statistical comparisons.

Our sample size calculation indicated that we needed to obtain 269 respondents, a representative sample size for young people in Birmingham based on the population of young people between the ages of 16 and 25 living in Birmingham being 197,044 (Office for National Statistics, 2015) at a 90% Confidence Level, with a 5% margin of error.

Appendix Three: The importance placed on patient centred care in the NHS, and the barriers to achieving a fully patient–centred NHS.

It is commonly agreed that the National Health Service is facing immense challenges. There are growing pressures on general practice services, whilst spend on services is relatively static (NHS England, 2013). Patients are expecting more from the healthcare system, which also needs to meet the demands of an ageing population and increased chronic illness, whilst working under unprecedented financial and workforce pressures. These pressures can, and have, led to low quality care and poor patient experience. The Francis report, following the inquiry into the failures of care at Stafford Hospital between 2005 and 2009, highlighted the dangers of targets and performance management overwhelming quality and compassion (Francis, 2013). Paradoxically a cultural and strategic shift within the NHS towards increased patient centred care is seen as a solution to the multitude of ills that the healthcare system is now facing.

A report compiled in 2011 for the Department of Health and NHS Institute for Innovation & Improvement stated that:

'Relational' aspects of care (like dignity, empathy, emotional support etc) are very significant in terms of overall patient experience alongside 'functional' aspects (access, waiting, food, noise etc) (Robert et al., 2011).

The RCGP inquiry into patient care in the 21st Century reported that:

'Our review of the evidence suggests that re-orientating the health and care system around a patient centred approach has the potential not only to improve health outcomes and quality of life for patients, but also to reduce avoidable demand for health and care services - and thereby help place the NHS on a sustainable financial footing.' (RCGP, 2014)

Unfortunately there is a recognition that person centred care is not yet happening and has a long way to go (Coleman, 2015). Healthwatch Birmingham recognises that the barriers to fully patient centred care are numerous, yet CCGs do need to overcome them if they are to meet the unprecedented challenges the NHS is facing.

In order for patient centred care to become a reality throughout the NHS, for all patient groups, more needs to be done than just training staff to be patient-centred. Although such training is necessary, it is unlikely to increase the level of patient centred care in a healthcare system of conflicting agendas (Fotaki, 2015). Many of the incentives and targets placed on NHS staff conflict with the delivery of patient centred care (Fotaki, 2015), making it difficult for healthcare professionals to provide patient centred care without financial penalty or risk (RCGP, 2014). It has been suggested that clinical guidelines, regulatory requirements and payment mechanisms need to be restructured to reward patient centred care (RCGP, 2014). Patient centred care will also require a shift in culture, demanding new ways of thinking about the dynamics of power between professionals and patients. The challenge of changing models of care, attitudes and behaviours should not be underestimated.

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