



Parent Carers and Health Checks – April 2015

1. Introduction

1.1 Amaze, PaCC and CCG

Since 1997 Amaze is the city's 'one stop shop' for information, advice and support for families with children with disabilities or special needs (SEND), covering areas like education, health, social care, leisure, finances/benefits and training/workshops. Amaze believes that parent carers are the experts, they know what they and their children need, they need to be engaged at all level of services provision for the child, for themselves and for the whole family. Amaze also manages the city's Disability Register on behalf of the Council and is in regular contact with families of about 1,600 children with SEND with active/up to date records on the Compass.

Amaze also hosts PaCC, a forum with over 240 parent carers signed up members who want to work collaboratively with statutory partners to help improve services and support. For example PaCC Parent Reps sit on various strategic boards within the city, it also organises focus groups and it gathers views/opinions and presents these to service managers to influence service delivery.

Amaze, hosting the Parent Carers' Council (PaCC), is one of Brighton & Hove voluntary and community sector groups contracted by the local Clinical Commissioning Group (CCG) to engage an involve traditionally excluded groups, in this case parent carers of disabled children and young people, around health care services. The local CCG funds Amaze and the PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children.

1.2 Transforming NHS Health Checks in Brighton & Hove

NHS and the local CCG are looking into transforming the way Health Checks are provided. A Health Check is a 20/30 minutes appointment which GPs offer to everyone between the ages of 40 and 74. It is a way to prevent heart disease, stroke, diabetes, kidney disease and certain types of dementia. The appointment is offered once every five years to anyone who has not already been diagnosed with one of the above conditions or has certain risks factors. If the health check comes back clear then there is not follow up, however if there is any problem the patient will be asked to see the GP.

While improvements have been made in prevention and treatment of the above conditions in the past years, prevention needs to be further improved. For

example cardiovascular disease (CVD) is a major cause of death and disability in UK and at the same time one of the biggest contributors to inequalities. More specifically in relation to Brighton and Hove findings from a local audit carried out in February this year called 'Preventing Premature Mortality Audit' highlighted the fact that too many people in the city suffer from poor health and die early as a result. Many of those deaths relate to cardiovascular disease, chronic obstructive pulmonary disease and diabetes, all preventable (<http://www.brightonandhovenews.org/2015/02/11/mortality-rates-suggest-that-too-many-people-in-brighton-and-hove-die-prematurely>).

The most important components of the way Health Checks are going to be transformed pivot around the idea that they will be mainly based within primary care with a more targeted service, e.g. focus more on people living in deprived areas of the city, a more active referral system, inclusion of mental health and wellbeing and cancer awareness, improved data collection, the provision of an outreach service and a 'guide' for GPs to better support follow ups (see Annex 1).

1.3 Parent carers and Health Checks

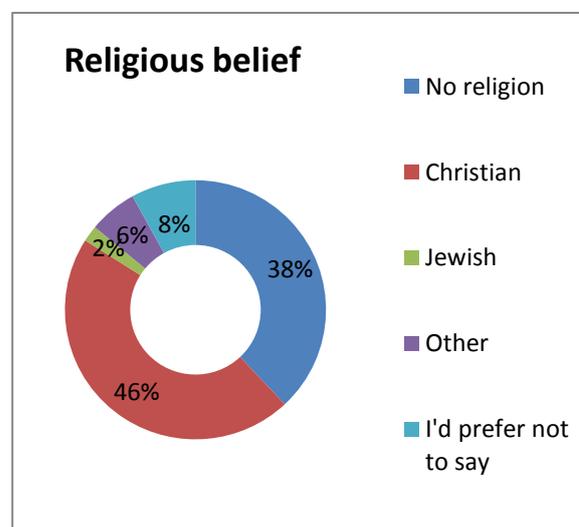
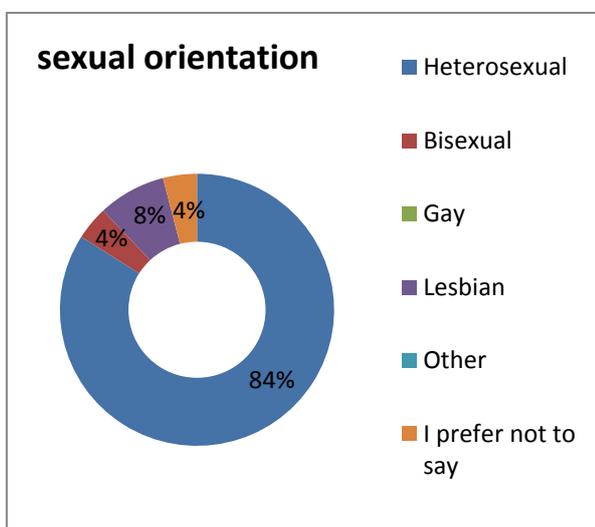
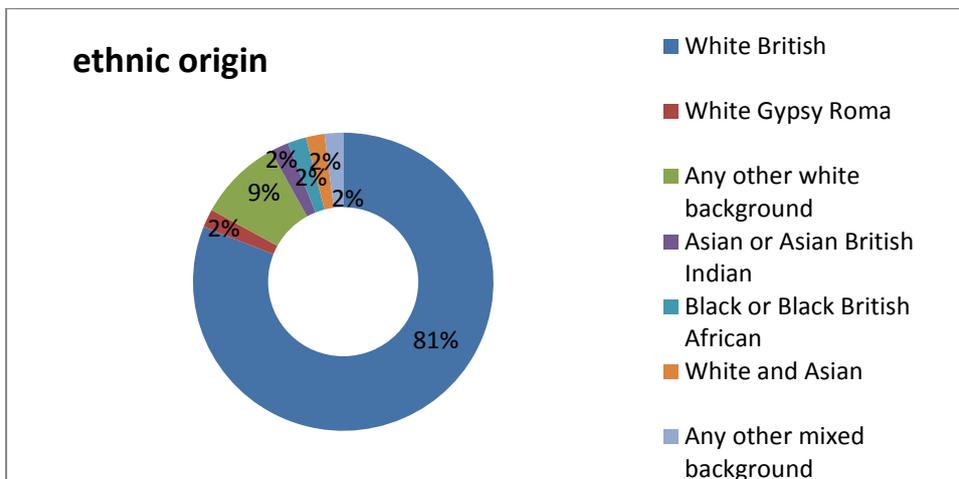
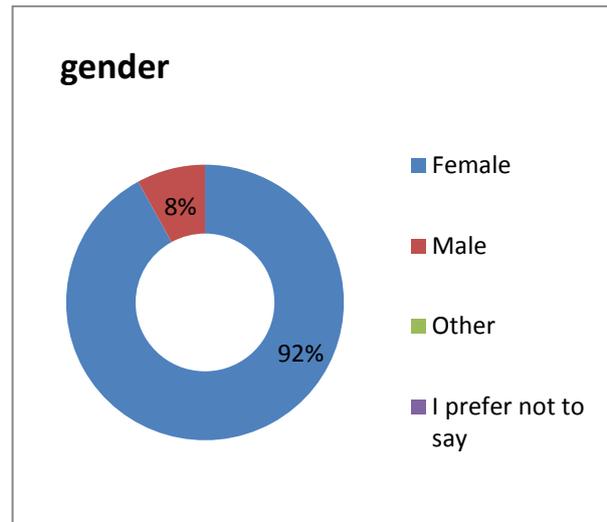
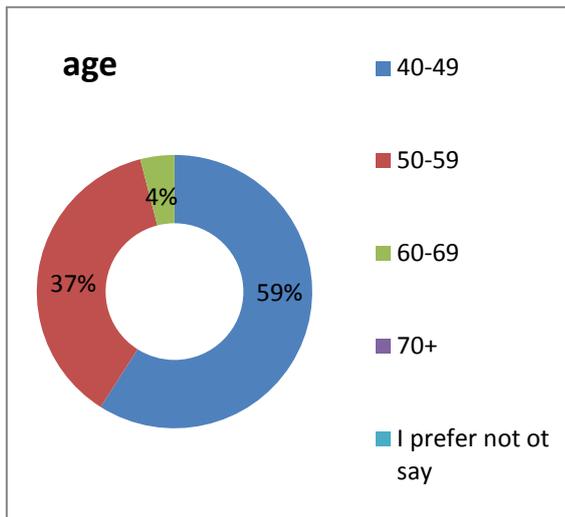
In July 2013 Amaze carried out a survey which was sent to every family in Brighton and Hove with a child registered on the Compass database (approx. 1812 CYP). The survey focused on the impact of caring for a child with disabilities on the carer themselves, including the carer's mental health and feelings of depression or isolation. One the findings was that 71% of respondents felt that they didn't look after themselves well enough or were in fact neglecting themselves. That increased to 85% if the parent had disabilities or additional needs. Only 27% of parent carers felt they had enough time to look after themselves. The reasons for such worrying results need to be further investigated however it is well known that parent carers feel overwhelmed with the needs of their child(ren)/siblings/ partner/household etc. that their own needs fall off the bottom of the list. (See Annex 2 page 5).

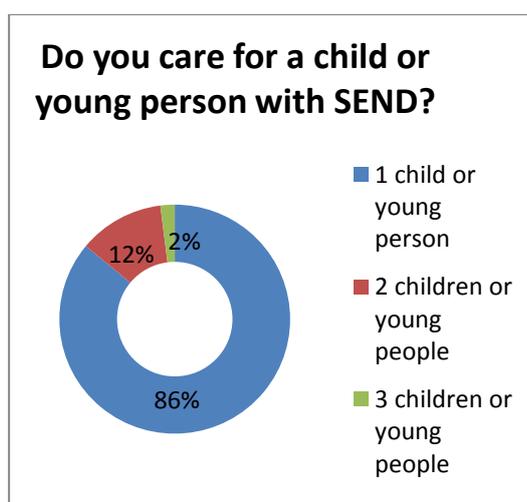
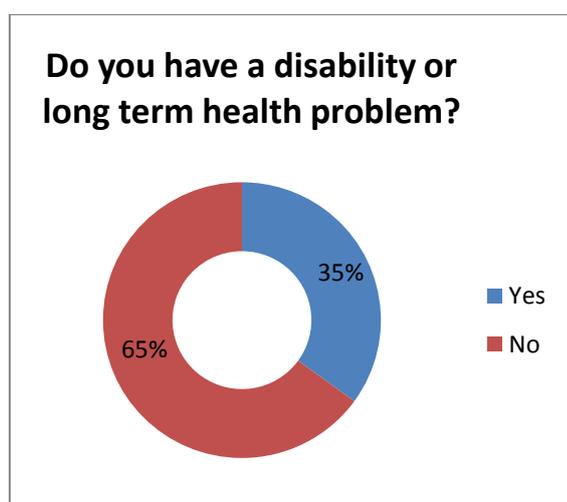
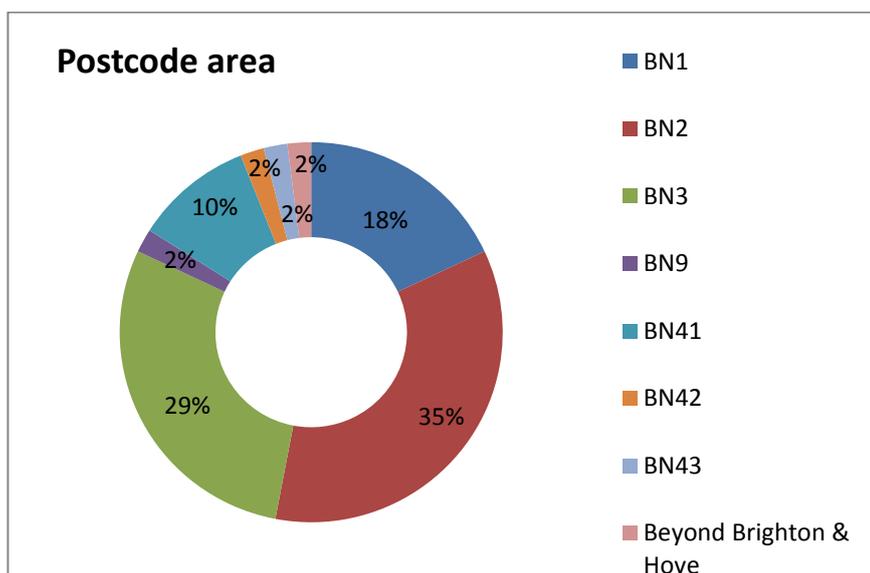
With this report we want to look into how Health Checks could be more responsive to parent carers' needs so that their health and quality of life can improve.

2. Methodology

For this consultation we used an online questionnaire which was adapted from the engagement questions on Nicola Rosenberg's handout (see Annex 1). The questionnaire was sent to parent carers who have a child(ren) registered on the Compass database and also to PaCC members and we used our social media to further publicise our consultation (see Annex 3). We received 49 completed questionnaires; data from questionnaires were collated into this report (see Annex 4).

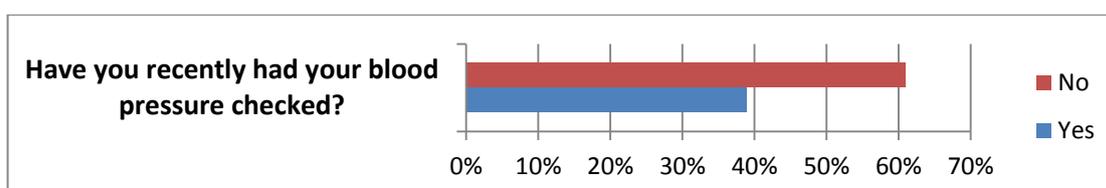
3. Demographic





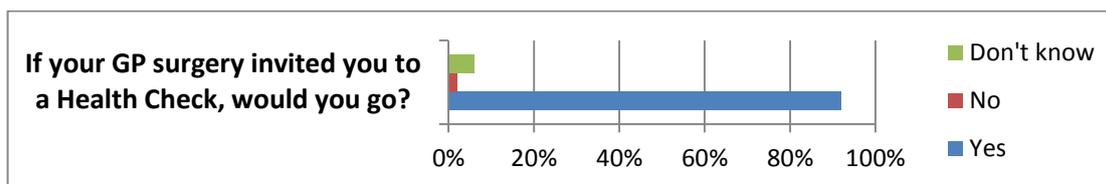
4. Findings

4.1 Measurement of blood pressure



Only 39% of respondents had a blood pressure check recently, whilst the **majority, 61%, did not respond to the question.** That is a worrying result as measurement of blood pressure reveals complications, for example hypertension. Hypertension is a risk factor for coronary heart disease and the single most important risk factor for stroke. It causes about 50% of ischaemic strokes and increases the risk of haemorrhagic stroke (<http://www.world-heart-federation.org/cardiovascular-health/cardiovascular-disease-risk-factors/hypertension/>).

4.2 Attending Health Check

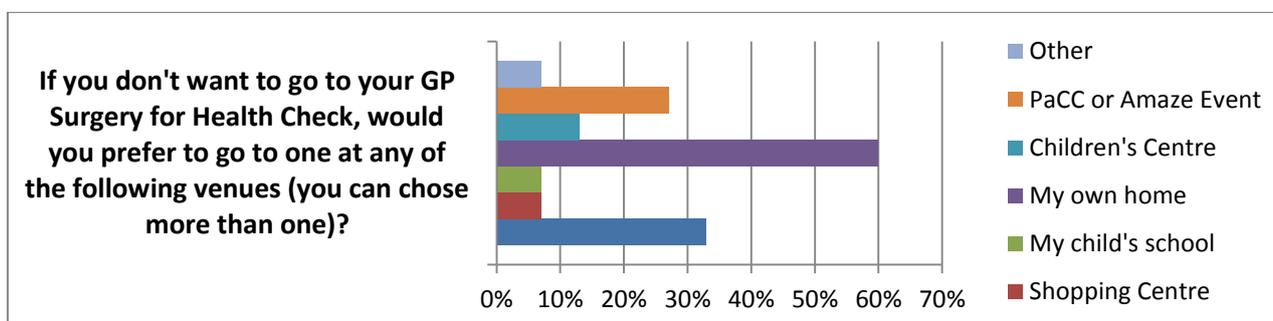


Interestingly **92% of parent carers who completed our questionnaire said they would attend a Health Check if invited by their GP**, 6% are not sure whilst 2% were resistant to attend because too busy or, one of the respondents:

"Our surgery is not very reliable, it's often more or less impossible to make an appointment there!! But if I was invited for a check-up of course I would happily go"

It is interesting to note that **nearly all the respondents were happy to attend a Health Check if offered one but a considerable number reported that they haven't checked their blood pressure recently**. Is that because they weren't invited to a Health Check or they just didn't receive the right information and/or urgency of the appointment?

4.3 Location

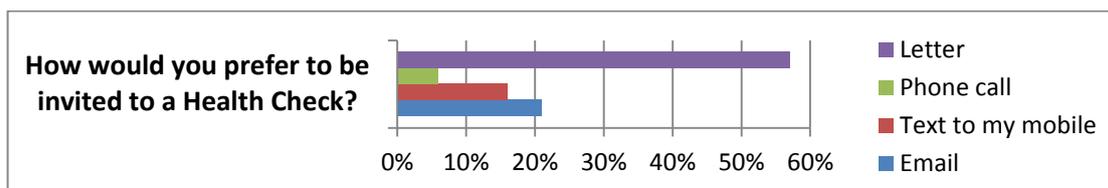


This question explores a bit more in depth the reason why perhaps people don't attend Health Checks if offered one. Would parent carers prefer to have a Health Checks somewhere convenient to them, not necessary the GP surgery? The majority of respondents, **60%, preferred to have a Health Check in their own home, 33% at a Community Centre, 28% at a PaCC or Amaze event, 13% in a Children's Centre** and smaller percentages in a shopping centre, in their child's school and other. A parent commented:

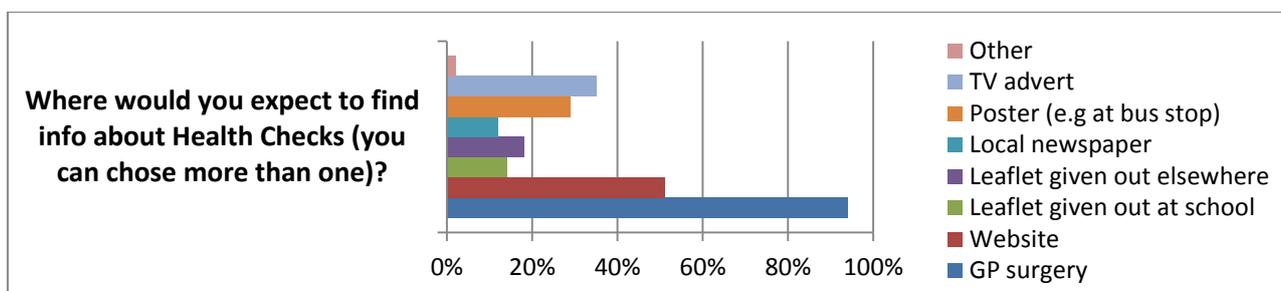
"I am just too busy"

Clearly the above reflects the parent carers' hectic daily life where most of time is occupied by looking after their child(ren) and the inability to look after their own health. Consequently the **possibility of having a Health Checks at home is very popular with our population of parent carers**. Interestingly the NHS is looking into providing this service and also into setting up an outreach service which would suit many parent carers.

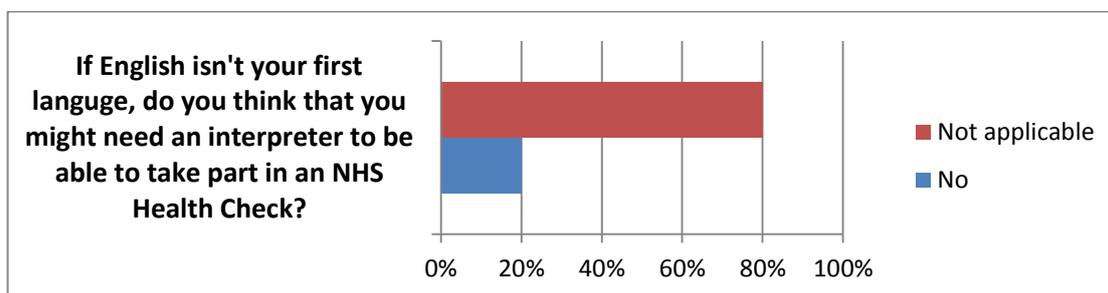
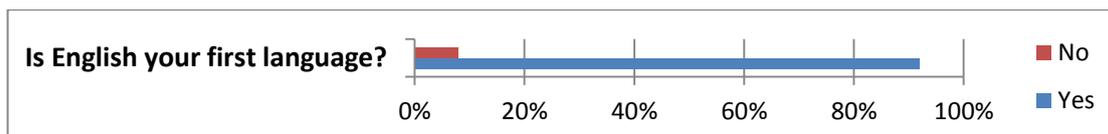
4.4 Communication



Parent carers prefer to be invited to a Health Check by letter, 57% of respondents, whilst 21% would like to be contacted by email, 16% by text to their mobile and only 6% through a phone call.



Information about Health Checks should be made available at the GP surgery, which was chosen by 94% of parent carers, whilst 51% expect to find out on a website. A more media orchestrated campaign of information was chosen by 35% - TV advert - and by 29% - posters- of respondents. Others preferred to find out through leaflets given out in schools or elsewhere and from local newspapers.



The majority of parent carers who responded to our online survey, 92% have English as first language. The remaining 8% don't need an interpreter to facilitate communication during a Health Check. However, this might be indicative of the parents having the language skills to complete our survey being those who wouldn't have needed an interpreter.

There is a clear indication towards GPs taking charge of planning and provision of Health Checks. **While invites and reminders will have to come from the GP, the need of a wider public awareness campaign, in different languages, would be beneficial to parent carers.**

4.5 Improving Parent Carer's health

We asked parent carers how their GP surgery could help to improve their own health. Some respondents are happy with the support they receive, whilst few respondents would like to receive more **information and support about losing weight and stop smoking**. One parent carer suggested **workshops, for things like breast cancer, and support groups, for things like stopping smoking, losing weight etc...** Also beneficial could be **regular health checks and more detailed guide lines on risk factors and links between health/illness and lifestyle**. One parent carer commented:

"I am lucky my surgery is very good. However by the time you have an appointment if you want to talk about stopping smoking or alcohol concerns you've probably lost the momentum. Perhaps if once a month, an open clinic where basics information about how the surgery help with the issues, would be good. A poster saying 10:30 Friday, open clinic talk on how we can help you stop smoking, book now!"

Some people expressed concern with the appointment system, for example waiting time to see someone too long and been put off by it. There was anxiety about 'troubling' the GP or NHS with minor concerns:

"[...] maybe nurse led clinics for health checks"

Interestingly, as we are aware of high incidence of mental health issues among parent carers, **some respondents would like to receive more help, ideally a bi-annual health check, with mental health issues, especially stress and anxiety caused by being a carer. The current offer of health checks focuses on physical health but we would urge a greater focus is needed to also prevent costly mental health problems.**

Better follow up was highlighted by a parent carer:

"When I went for a celestial test at my GP no one got back to me after many phone calls to my surgery I was told by reception "it's a bit high but not to worry" and there's been no follow up or nothing"

One parent carer suggested:

*"**Looking at one's wellbeing in a more holistic way** and offering alternative therapies if that would be beneficial in order to avoid more serious medical conditions"*

Whilst another commented:

*"Having a well-woman clinic at which you could have these appointments. Being more supportive. Giving practical and financial help with things such as gym membership and complimentary therapies. **Concentrating on keeping people well rather than treating illness**"*

5. Recommendations

- **Parent carers, not only those from most deprived areas, should be specifically targeted and invited for Health Checks**
- **Health Checks provision should be broadened to include home visit and also be offered at PaCC and Amaze Annual Info event (November) and also at Community Centres**
- **Information and importance of Health Check to be more visible. Parent Carers to be sent a letter with clear guidance and notes on potential follow ups**
- **GPs to set up information groups and workshops where parent carers can find out more about Health Check and services available to improve their health**
- **An outreach service should support those parent carers who cannot attend GP surgeries and also offer a pop-up clinic at events or community centres**
- **A better holistic system which help parent carers staying healthier for longer and better follow up system after attending Health Check**
- **Extend the focus to also consider, predict and prevent mental health problems**

6. Annexes

Annex 1: Health checks involvement event 17th Dec 2014

Annex 2: Analysis of the Amaze Parent Carer Questionnaire July 2013

Annex 3: PaCC Survey on NHS Health Checks

Annex 4: New Summary Report - 04 March 2015