

User engagement research – final report
ecd p, June 2011

Contents

1.	Introduction and context	3
	About this work.....	3
	About HealthWatch	3
	HealthWatch in Essex: progress so far.....	3
	Summary of how this work was undertaken	4
	Summary of people engaged	5
2.	Scope of the work	6
	A note on individual / collective engagement	6
	A note on language	7
3.	Understanding engagement	8
	Opportunities for engagement: the commissioning cycle	8
	The involvement continuum	8
	Reasons why people don't engage with health/social care systems	10
	Reasons why people do engage with health/social care systems.....	12
4.	Understanding Essex.....	14
	Current demography	14
	Future demography.....	15
5.	Summary of engagement work in Essex	17
6.	Options for user engagement: what works and what doesn't work?	20
	Practical mechanisms for user engagement.....	20
	People's views on the most effective mechanisms for user engagement	34
	Discussion on effective mechanisms for user engagement.....	41
7.	Conclusions and recommendations.....	43
	Recommendations	44
	References	47
	Annex 1 – full quantitative details of engagement.....	49
	Annex 2: ecdp's lived experience approach.....	51
	Mechanisms	51
	Lived experience in practice.....	52

1. Introduction and context

About this work

“People do not know how to share views, but they’ve certainly got views. There’s a whole group of people not being listened to” – Focus group attendee

This work was commissioned to seek and report upon the views of disabled and older people (including, but not exclusively, service users) on how their issues and experiences can be best captured, analysed and articulated to shape and influence the commissioning agendas of health and social care agencies in Essex.

Its focus is on:

- How effective are different, practical mechanisms for capturing people’s voices
- How these practical mechanisms can be developed and deployed in the future.

The work needed to pay particular attention to the potential role of HealthWatch in Essex, as well as complement a parallel piece of research which concerns the role of small and medium size voluntary and community sector (VCS) organisations in shaping and influencing the health and social care commissioning agendas.

About HealthWatch

As part of the Health and Social Care Act 2012, the Essex and Southend Local Improvement Network (LiNK) will be replaced in Essex by a new body called HealthWatch. This organisation will represent the needs and views of service users in the commissioning of health and social care services in Essex.

The government plans for local HealthWatch organisations will see them:

- Carry out statutory functions
- Be corporate bodies, embedded in local communities
- Act as a local consumer champion representing the collective voice of patients, service users, carers and the public on statutory health and wellbeing boards
- Support people to access information and independent advocacy if they need help to complain about NHS services
- Have influence with commissioners, providers, regulators and HealthWatch England, using their knowledge of what matters to local people
- Play an integral role in the preparation of the statutory Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies on which local commissioning decisions will be based.

Furthermore, local HealthWatch will have a place on the local Health & Wellbeing Board.

HealthWatch in Essex: progress so far

A consultation exercise carried out in March 2011 resulted in a successful bid to the Department of Health for Essex to become a local HealthWatch pathfinder. By April 2013, HealthWatch Essex will be fully established as a statutory body.

Following discussions around which models of membership would best support HealthWatch Essex represent the voices of patients and the public, members of the Pathfinder Executive were appointed in January 2012.

Membership is made up of people with relevant skills and experience, who together represent the diversity of Essex. The Executive will lead the development of the HealthWatch Essex Pathfinder.

The Pathfinder Executive will design and develop its structure and approach to enable HealthWatch Essex to move to a corporate body with statutory functions by April 2013.

The HealthWatch Essex Pathfinder will establish an organisation rooted in communities and responsive to their needs. This will mean working with existing local community networks and ensuring they have maximum reach across Essex. The Executive – made up of 24 appointed public representatives from across Essex – will work with the public to develop a network of members who can make a contribution to its work.

Further information on HealthWatch Essex can be found here: <http://www.essex.gov.uk/Business-Partners/Partners/Adult-Social-Care-providers/HealthWatch/Pages/What-is-HealthWatch.aspx>

Summary of how this work was undertaken

This work was undertaken in four main stages, beginning in March 2012 and culminating in this report.

Stage 1: Desk-based research: Desk-based research rapidly identified the relevant research on effective user engagement (particularly in health and social care), as well as on existing engagement mechanisms in Essex. To do this, we searched for the terms “engagement” and “involvement” in the following locations:

- Department of Health
- NHS Evidence website
- NHS Confederation
- NHS People and Participation project
- Think Local, Act Personal
- Involve
- Joseph Rowntree Foundation
- Social Care Institute for Excellence
- King’s Fund
- Health Foundation
- Office for Public Management
- Sainsbury’s Centre for Mental Health
- National Development Team for Inclusion
- National Council for Voluntary Organisations
- Third Sector Research Centre.

As a result we identified approximately 80 publications, articles, websites, guides etc., of which we analysed 25 in depth.

We also reviewed the demographic profile of people in Essex to ensure our work reflected as far as achievable the Essex population, particularly ensuring marginal and seldom-heard groups were included (the results of which are in Section 4).

Stage 2: Communications and quantitative user research: Early in the research we publicised the work through printed, electronic and social media to ensure as many people as possible were aware of it. We also published an online survey to deliver the quantitative user research aspect of the project. A summary of the number of people reached is included below. Full details are in Annex 1.

Stage 3: Qualitative user research: This stage formed the bulk of our work, and was made up of 4+1 focus groups across the county. The “+1” focus group was specifically for older people and was delivered in partnership with Age UK Essex.

Stage 4: Analysis, reporting and recommendations: All data from Stages 2 and 3 was collated, analysed and fed into this report. This report is being produced for debate and discussion at a meeting

with the HealthWatch Essex Pathfinder Executive Board in July 2012. A further version will also be produced and disseminated to all interested stakeholders.

Summary of people engaged

In total we engaged directly with 121 people for this work and indirectly engaged with over 470 people and 21 organisations. We also distributed almost 1,000 separate pieces of promotional material to other stakeholders across the county.

The 121 people we directly engaged with included:

- 16% people with learning disabilities
- 33% people with physical or sensory impairments
- 17% people with long-term health conditions
- 11% people with mental health conditions
- 6% carers.

Some 52% were female and 44% were male and they covered all parts of Essex with the exception of North West Essex.

Full details are included in Annex 1. Where findings in this report differ by, for example, impairment group or age, these differences are drawn out below.

2. Scope of the work

It is important that a relatively small scale piece of work such as this makes clear what it does and doesn't seek to do.

This research set out to work as far as achievable with all groups represented within the demography of Essex. This included:

- People with learning disabilities
- People with long-term health conditions
- People with mental health conditions
- People with physical and/or sensory impairments
- Young people
- People from BME backgrounds
- LGBT people
- Gypsy, Roma and Traveller communities.

Nevertheless, our level of success in involving and including these different groups of people varied. Of course, for a piece of work that is about how best to effectively capture people's views this raises an interesting subplot. However, experience and observation from undertaking this work itself – what did and didn't work, what might be done differently next time, as well as drawing on wider experience – is drawn on throughout.

There is a considerable range of mechanisms for enabling people to participate in public service reform (see Section 6). Within this piece of work it was simply not feasible to ask people to consider each one of these mechanisms. The quantitative and qualitative research therefore focused on a reasonably-sized subset of these mechanisms, the reasons for choosing which are also highlighted in Section 6.

As much as possible, the report aims to add to existing literature rather than replicate it. However, in ensuring good treatment of this important issue we have included relevant information that ensures the practicalities of involvement are set within a context that makes that involvement meaningful. Effectively gathering the views, issues and experiences of people must be for a reason, and not simply be an end in itself.

As a result, this research shouldn't be considered as a standalone piece of work. It contributes to wider work going on in Essex (and beyond) to continue to develop the best health and social care services possible. This is both specific to the work that HealthWatch Essex does, as well as to the work of other relevant stakeholders in engaging people and communities, not least of which are local authorities, Clinical Commissioning Groups and any others who deliver a public service.

Finally, this work is practical in intent. The key sections – Section 7 (Summary and Conclusions) and Section 8 (Recommendations) – aim to provide practical suggestions for the representatives and officials tasked with ensuring effective engagement of people in health and social care in Essex.

A note on individual / collective engagement

The brief for this work is clear in that it covers *collective* engagement mechanisms rather than *individual* ones. That is, it focuses on effective ways of giving a "joined-up" voice people and involving them in shaping services and determining local priorities, rather than an individual's particular experiences.

A practical effect of this is that the report doesn't touch on, for example, the important issue of advocacy as a mechanism for capturing or representing an individual's views or to support them in navigating the health and social care system. Similarly, the report doesn't pay significant attention to the issue of capturing individual comments and complaints, though there is clearly a requirement for

this to happen (see table in Section 6) and people engaged in this research assumed that comments and complaints were analysed.

It is reasonable to say that a noticeable number of people who participated in the focus groups were frustrated with the health and social care systems and their own (occasionally recent) experience of them. While facilitators emphasised that this was not the focus of the groups, these frustrations often crept to the surface during discussions. In each case, if appropriate, individual follow-ups were undertaken with each person, but the wider conclusions to be drawn are:

- (1) The importance of managing expectations through clear communication of the purpose of engagement from start to finish
- (2) Good facilitation that can help to mitigate or minimise a discussion focusing on individual experience
- (3) The vital importance of the role of HealthWatch Essex in addressing this undercurrent of frustration.

A note on language

We use “people” throughout this report as a shorthand for service user / client / customer / patient etc. Also, where we refer to the “local authority” we use this as a shorthand for all public bodies in Essex whose work should engage people. Finally, for the purpose of this report, we use the terms “engagement” and “involvement” interchangeably.

3. Understanding engagement

Before considering the practical mechanisms for engagement, it is useful to set the context within which engagement happens and to remind ourselves of the typical reasons why people do or don't engage with health and social care systems. Practical suggestions arising from these are given in Section 0.

Opportunities for engagement: the commissioning cycle

The commissioning cycle captures in a straightforward, if not slightly idealised way the different stages and many opportunities at which people can be engaged in health and social care commissioning. The commissioning cycle is made up of four broad stages. These are: (1) Analyse, (2) Plan, (3) Do, and (4) Review.

A fuller description of the steps within the commissioning cycle is shown in the figure on the following page.

The involvement continuum

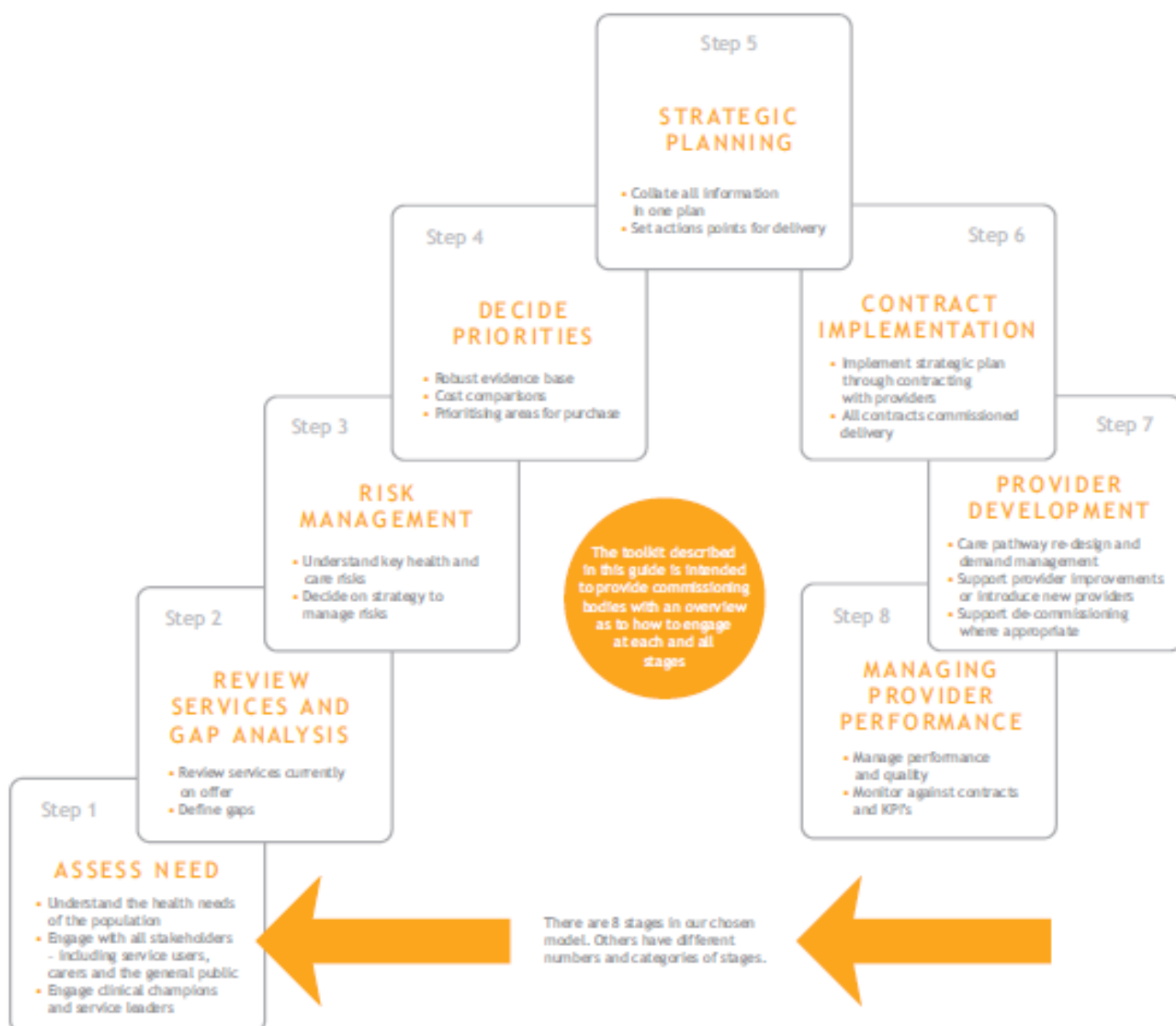
There is a well-established “involvement continuum” which captures the different levels at which people can be involved in public service systems such as health and social care. This is summarised in the table below¹, with examples of techniques associated with each of the levels of engagement.

Minimum Involvement		Maximum Involvement		
Giving information	Getting information	Forums for debate	Participation	Partnership
Exhibitions	Surveys and questionnaires	Meetings with existing groups	Health panels	Community development
Leaflets and other written documents	One-to-one interviews	Public meetings	Citizens juries	Working with lay representatives
Local press or radio	Citizens' panels	Focus groups	Open space events	Service user forums
Etc.	Etc.	Seminars	Etc.	Etc.
		Café consultations		
		Etc.		

This continuum provides a useful framework in which to consider the practical engagement mechanisms that are discussed at length in Section 6. It is important to note that different levels of engagement are appropriate at different times and points of the commissioning cycle.

¹ From Department of Health (2003), Strengthening Accountability: Involving patients and the public – practice guidance
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4074292.pdf

Figure: opportunities for engagement²



²From North West Mental Health Improvement Programme (2011), Engagement in the Commissioning Cycle: A Guide for Service Users, Carers, the Public, GP's, Commissioners and other stakeholders in Mental Health Care Services <http://www.nmhdu.org.uk/silo/files/engagement-in-the-commissioning-cycle.pdf>

Reasons why people don't engage with health/social care systems

There are many reasons why people do or don't engage effectively in sharing their experiences with commissioners. These hold equally for both health and social care systems – people typically didn't differentiate between the two.

Before discussing them, though, there is a fundamental point to note: the people engaged by this work represent a relatively small minority of people. In general, and as other research has found, it is not a typical consideration or pastime for people to engage in shaping the health and social care system (nor, indeed, public service delivery as a whole).

Some of the reasons why people don't engage include:

- Structural or expectation barriers
 - Track record of public services failing to respond to results of previous engagement
 - Lack of commitment from public services to change as a result of engagement
 - Professional attitudes often meaning engagement isn't taken seriously
 - People being able to respond only to "official", top-down agendas rather than generate "bottom-up" ones
 - Consultation fatigue, e.g. the same groups of people are routinely consulted or engaged (whether or not the issue is relevant to them)
 - It's the "usual suspects" who take part
 - Limited consideration of opportunities for conflict between people and how this can be managed / addressed / minimised
 - Insufficient time within the commissioning cycle for effective engagement
- Practical / process barriers
 - A non-welcoming or unfriendly approach
 - Using just one mechanism for engagement
 - Engagement held at limited times or locations
 - Insufficient resources – particularly financial and human – made available to underpin effective engagement
 - No travel costs, payment for time or expenses
 - They didn't know engagement was happening
- Personal barriers
 - Limited training or support for people to overcome personal feelings to participate
 - Lack of confidence or assertiveness
 - Low levels of literacy
 - English not as a first language
 - Lack of interest e.g. an organisation wishes to engage on an issue which they perceive as important but which is of no direct interest to most people
 - A feeling that engagement is one-off or tokenistic
 - A feeling that attitudes – from professionals or from other people – can or could be discriminatory
 - Not enough time
- Technical barriers
 - Exclusive, technical or jargon language
 - Lack of accessible formats
 - Lack of wider reasonable adjustments
 - No technological support

Many of these reasons were cited by participants in our dedicated focus groups.

The most significant of these – both in terms of the number of times the issue was raised and its implications – was the question of whether engagement was meaningful. On this there was significant scepticism from the majority of participants. The two main worries were best encapsulated in the following quotes:

"There is too much box ticking [and] too much impact analysis after a decision has already been made."

"If HealthWatch is going to listen to us, who is going to listen to HealthWatch?"

A very pragmatic – and pertinent – point was also highlighted on the issue of meaningful engagement, in the context of the current focus on local authority budgets:

“Why are people wasting money asking us, if they are not going to do anything?”

Some people who participated felt that they often shared their views but were unsure of the impact this had, having been given no indication of whether this had been seen by those with the ability to make changes.

Here an interesting difference emerged: most focus group participants had wanted their feedback to be acknowledged by managers or others. This could be done in any number of ways: email, post, phone call, online etc. More often than not, though, this hadn't been done. For a minority of participants, a response was unimportant as long as their feedback made a difference or a change was made as a result of their input. Most felt they would understand if their feedback or ideas could not be actioned, as long as a response or explanation – from a suitable person – was given.

Thus, for some people acknowledgement and explanation was important; for others, knowing their feedback had made a difference or effected a change was what mattered most.

Older people in particular were reticent about sharing their feedback for one main reason: fear of losing services or receiving a worse service. Participants at the Age UK focus group all agreed that their generation were brought up to respect and not challenge professionals and so almost feared complaining or “making a fuss”. Older people also felt that they were less likely to receive a positive reaction from professionals when offering feedback than younger people:

“Reactions from managers completely change depending on [your] age.”

Our survey also shed some light on which of these reasons is more prevalent as to why people aren't engaged. Overall, 40% of our survey respondents hadn't shared any views on the health and social care systems. By far the biggest reason (58%) was that they didn't know how to.

“If I hadn't come here [a focus group] I wouldn't have known who to talk to.”

After this, it was a feeling that it wouldn't make any difference (42%) that prevented people sharing views. One third felt they didn't have enough time to contribute – something beyond the control of commissioners.

The full results are presented below:

What would stop you wanting to share your views on how health and social care systems work? (Please tick all that apply)		
Answer Options	Response Percent	Response Count
<i>Structural barriers</i>		
Involvement isn't taken seriously by health / social care managers	55%	16
It's always “the usual suspects” who take part	38%	11
Too much jargon	35%	10
Consultation overload	24%	7
My views won't make a difference	21%	6
		50
<i>Practical / process barriers</i>		
Lack of time to take part	52%	15
Meetings are held at times of day I can't make	45%	13
No payment for time	17%	5
Lack of transport to meetings / events	17%	5
No payment for travel expenses	14%	4

What would stop you wanting to share your views on how health and social care systems work? (Please tick all that apply)		
Answer Options	Response Percent	Response Count
		42
<i>Technical barriers</i>		
Lack of accessible information	21%	6
No technical support for using online tools	7%	2
No training or support to take part	7%	2
		10

This suggests that structural and practical/process barriers are by far the most significant when it comes to reasons for people not engaging.

The question of payment for people sharing their views deserves some closer attention. Nearly two-thirds (63%) of survey respondents didn't think that people should be paid to share their views. It was stressed that people shouldn't be out of pocket for having contributed, such that travel costs, food or refreshments should be provided – a view most people (96%) agreed with.

Nevertheless, there were 3 main reasons why it was felt people shouldn't be paid:

1. There is a cost associated with this that local authorities can't afford; the money should be used instead directly for service provision
2. A cash incentive may mean some people contribute their views for the wrong reason
3. Sharing views serves a democratic purpose that should be valued in its own right, without the need for explicit payment.

Of those who felt that people should be paid for their involvement, there was recognition that payment should depend upon the level of involvement.

A light-hearted effort to summarise some of the above barriers is provided by the Exeter Senior Voice's guide to 'How to Make Sure Marginalised People Stay Marginalised'³. It sums up the practices that prevent participation from becoming meaningful and includes the following advice:

- Remember the "easy to reach" are easier to reach
- Only invite the usual suspects – they understand how meetings work
- Never divulge how you're going to use the information they give you
- Make sure every letter comes from a different person, and don't give out a contact number
- Management terms, jargon and abbreviations should be used throughout
- Choose a venue with only two lavatories, and they're on another floor
- Make people pay for the privilege of being consulted – do not reimburse expenses, or if you must, make them ask about it
- Keep it simple – you only have to say you've tried. Limit your consultation to one public meeting, in the evening.

Reasons why people do engage with health/social care systems

Of course, the opposite of many of the above barriers would be reasons why people do engage in questions relating to the health and social care system. As well as these reasons, there is also a wider set of reasons why people get involved.

Almost all focus group participants were motivated to share their views because of a personal experience as a user of health or social care services. Although this was often around issues that people recognised as affecting others, it was their own experience which had initiated their interest.

³Quoted in SCIE (2007), Practice guide: the participation of adult service users, including older people, in developing social care, <http://www.scie.org.uk/publications/guides/guide17/files/guide17.pdf>

This finding was echoed in our survey: 76% of people wanted to share their views on health and social care because of personal experience.

Perhaps unsurprisingly, it was almost always a negative experience that they had offered feedback on. Indeed, a large number of the focus group participants didn't consider positive feedback during the discussion until it was explicitly mentioned. Some, however, had given positive feedback because they felt it was important to note when things worked well too. Most of these people talked about writing letters uninvited, rather than responding to requests for feedback.

The full results from our survey on people's motivations for sharing their views are presented below, and reflect the qualitative analysis above.

What motivates you to want to share your views on how health and social systems work? (Please tick all that apply)		
Answer Options	Response Percent	Response Count
To make the systems better for everyone	90%	26
Personal experience – good or bad – of the health and social care system	76%	22
To highlight problems with the current systems	66%	19
To make more people aware of what services are available for them	52%	15
To have a voice	38%	11
To get to know other people using the health and social care system	35%	10
To be an influential person	14%	4
To help develop my own skills	24%	7

The very practical question of how people found out that engagement was happening in the first place is one to which we have an anecdotal sense of an answer: people found out through the following mechanisms (which aren't exhaustive), roughly in the order listed:

- Local voluntary sector organisations (especially CAB, Age UK, Mencap, **ecd** etc.)
- Local newspaper
- Word of mouth
- Online (websites, social media)
- Local library
- Existing engagement mechanisms
- Local elected representatives, especially MPs
- PALS.

It is noticeable that many of the mechanisms ECC itself has identified for engaging users – summarised in the table in Section 5 – were rarely mentioned by people engaged in this work. Where people are aware an organisation works to influence the health and social care system in Essex, they tended to be more likely to have felt they had chance to contribute their voice. However, this was far from the norm within the people involved in this work.

4. Understanding Essex

Current demography

The following provides a brief overview of the key demographic statistics relating to Essex. All statistics below are drawn from **ecd**p's paper on the demographics of disabled people in Essex⁴.

Population

The population of Essex is 1.66million (JSNA 2008). ONS data shows that between 1998 and 2008 the Essex population grew at an average rate of 0.7% per year and is projected to grow to over 1.9 million (14% increase) by 2029.

Gender

Overall, men make up 48.8% of the population of Essex. Women make up 51.2% of the population.

Males slightly outnumber females up until the age of 30. Of the population aged 65+ around 56% are women and by the age of 85+ this figure has increased to over 68%. These differences are largely due to consistent patterns of longer life expectancy in women.

Age / Life Expectancy

As the population continues to live longer, levels of impairment will continue to increase also. This means it is important to examine the age distribution of the county.

Compared to England as a whole, Essex has proportionately more younger and older people.

Tendring has the highest proportion of older people in the East of England, (1 in 3 residents over 65). Within this district Clacton-on-Sea and Frinton-on-Sea have a high population of retired people. Castle Point also has a relatively older population (1 in 4 residents over 65).

Life expectancy (indicating many other social and economic factors) varies hugely across Essex. In Southend it is 78.1 and in Thurrock it is 78.2 (this is still near the average for England, which is 78.3), but in Uttlesford it is 88.7 (potentially indicating a better quality of life or care).

Lower life expectancies are more common in vulnerable groups, such as gypsies/travellers or those with serious mental illness.

Disability Statistics

According to the General Household Survey 2002, about 21% of the total adult population is disabled. No robust figure for an equivalent figure for Essex currently exists. However, approximately 16% of the Essex population declared they have a limiting long-term illness – a reasonable proxy measure. Among Essex working-age population (16-64) around 121,000 people (2005 figures) declare an impairment.

Disability across Essex can be split by impairment group as follows:

⁴ **ecd**p (2010), Disabled people in Essex – understanding the demographics:
<http://www.ecdp.org.uk/home/2010/4/7/disabled-people-in-essex-understanding-the-demographics.html>

Table: Impairment groups as percentage of total population

	Physical impairment	Sensory Impairment	Learning Disability ⁵
National	2.7%	0.22%	0.39%
Essex	3.2% (higher)	0.12 % (lower) 4.6 % when including those with a secondary or mild impairment	0.35% (lower) but 0.44% are registered with a learning disability (this rises to 7.2% in Tendring and 6.6% in Colchester)

Older People, Disability and social care

It can be difficult to estimate the rate of impairment in older people for a number of reasons. Firstly, perhaps having had few or no health issues throughout their lives, they may not consider that the health problems they have acquired at a later stage in life qualify as impairments. Secondly, they may not qualify for (or seek) the type of the care that includes them in statistics such as those below. Finally, older people can be overlooked in medical and care systems and some people may have undiagnosed or untreated conditions. The rate of long term illnesses is at its highest among older people.

In 2005-6 the rate of older people (over 65s) receiving social care in England was 15.77%. In Essex, this figure was 15.11%, slightly lower than the national average.

Lesbian, Gay, Bisexual and Transgender (LGBT) Groups

The government estimates that between 5 and 7% of the population is lesbian, gay or bisexual. We do not have any specific statistics relating to Essex.

Black and Minority Ethnic (BME) Groups

According to the 2001 Census, people from non-Caucasian groups made up 5.5% of Essex residents compared to across England where 13.0% of people belonged to BME groups. In 2001, people from BME groups made up 2.9% of Essex residents. White minority groups (such as Polish people) made up 2.6% of the Essex population.

Recent estimates, however, state that 8.6% of Essex's residents are from BME groups, which demonstrates the Essex BME population is growing in line with national averages.

Gypsy and Traveller Community

There are 11 registered Gypsy / Traveller sites in Essex (with the capacity for 305 caravans) which are residential rather than transient. The county is host to over a third of the East of England's unauthorised developments, many of which are in Basildon. Essex hosts the largest Traveller site in Europe and has the highest concentration of Travellers nationally.

Future demography

Population growth is a significant factor for the East of England and Essex in particular. By 2031 the East of England will be the second fastest growing region in England, with a population increase of more than 25% from 2001. During this period, Essex is expected to see the highest numerical change of all counties in the East, absorbing some 324,000 additional residents – more than three times the population of Harlow.

⁵ Number of people with a learning disability supported by social services

Essex has an ageing population. The concentration of over-65s will increase dramatically, a national issue that will be magnified in Essex: 13% of local people are within ten years of their sixty-fifth birthday; over 26% are within twenty years.

Essex will see increases not just in the over-65s, but in the over-75 and over-85s too. By 2031, Essex's over-85 population will have more than doubled from 30,800 to over 77,000. This represents 5% of the Essex population, compared to over-85s making up 4% of the national population. By 2031 there will be more people over 60 than under 20, making the Essex population look a lot more like places previously seen as retirement towns.

An ageing population places pressure on health and care services. Hospital and community health expenditure on those aged 65-84 is double the average for people in the population as a whole, while expenditure on those aged 85+ can be over five times as high. Essex social care services currently support around 20,000 older people in their own homes and 5,000 in residential settings. Demand for these services in Essex could increase by over 80% as the population continues to become older and live longer, placing increasing strain on limited care budgets.

5. Summary of engagement work in Essex

A recent paper⁶ by Essex County Council reviewed user engagement specifically in Adult Social Care in Essex, to understand how ECC engaged with citizens and services users, and to identify where improvements at both a strategic and implementation level needed to be made.

The key findings of this report – all of which still hold, and which are drawn upon in the recommendations of this report (see Section 0) – were as follows:

- User engagement needs to be planned into projects, and undertaken at an earlier stage of the commissioning process
- A strategy to engage with seldom heard groups is required, and needs to coincide with similar efforts across ECC
- Greater use should be made of community-based, local engagement mechanisms
- There needs to be a much greater use of online user engagement
- Engagement methods need to be flexible enough to adapt to the commissioning process
- User engagement could be enhanced by greater work with health and other partners
- There needs to be a tool to evaluate user engagement mechanisms
- User engagement success needs to be highlighted to demonstrate its value.

The report provides an overview of the then existing methods of engagement for Adult Social Care in Essex, which is reproduced below.

Table: Overview of Adult Social Care engagement mechanisms	
Engagement mechanism	Purpose / Objectives / Description
Planning Groups <ul style="list-style-type: none"> • Older Peoples' Planning Group • Deaf Essex Access Forum • Hard Of Hearing Planning Group • Deaf Blind Planning Group • Physically Impaired Planning Group • Visually Impaired Planning Group 	Planning groups are designed to allow local service users of different groups the opportunity to "have their say" and provide feedback to the council. All planning groups have terms of reference and the key point within this for the purposes of service user engagement is "to give a voice to disabled people/service users and carers... by engaging with and influencing Adult, Health and Community Wellbeing (AHCW) plans and delivery of their services." It is part of the Essex County Council Public Engagement Strategy (2008) to support service user groups.
Participation Network Forum (PNF)	The PNF is designed to get groups and organisations that work in Essex together for the improvement of service delivery and to influence commissioning and planning in ECC. The groups that get around the table can offer advice and guidance to each other and to ECC.
Options for Independent Living (OIL)	The Oil Transport group is made up of disabled and older people of various impairments. It also includes disabled people's organisations including ecd p, Disability Essex and Essex

⁶ Essex County Council (2011), Ensuring the Commissioning Process is influenced by User Engagement: Formulating an agreed approach across Adult Social Care

	Access Groups plus transport providers and the government transport watchdog passenger focus. Its purpose is to improve access to transport for disabled and elderly people, with a focus on the social model of disability and equality and discriminatory demands.
Making Involvement Matter in Essex (MIME)	MIME is focused on people with mental health conditions and seeks to give them a voice in terms of the services they receive and how they are treated. It trains service users to be active participants in the planning of mental health services. MIME also seeks to improve commissioners' skills when engaging with mental health service users.
Local Involvement Network (LiNK)	The LiNK is designed to be a voice for the citizens of Essex and Southend, holding healthcare and social care providers to account and identifying needs.
WhyNot! Group	The WhyNot! is a group of older people trained for ASC by ARU to be researchers. They are an effective research group for older people. The group is approximately 12 in number with a new cohort coming through boosting the numbers to 20. They operate throughout the whole of Essex.
Engage Essex Website	The Engage Essex website is promoted as the place for all online public consultations for ECC. Its purpose is to provide an easy, cost-efficient service that can reach many people.
Carers' Participation Board	The CPB is designed to give informal carers a voice in the council. Seeking opinion and consultation on strategy and service provision.
People's Parliament	The Essex People's Parliament is a group run by people with a learning disability with help from Social Care Services and members of the Partnership Board. Members of Parliament (MEPPs) are elected throughout Essex to attend meetings to discuss issues.
Essex Carers' Network (ECN)	The ECN assist and represents carers of people with learning disabilities. They meet regularly to inform carers and to gather information, raising concerns and success to ECC to influence service delivery. They make sure carers are aware of local and national events.

Local Action Groups (LAGs)	The LAGs are local groups (in each district) that seek to assist and represent people with learning disabilities, ensuring they have access to good services and know about them. The LAGs also liaise with the council to assist with its commissioning and planning. Each LAG has an experienced co-chair who leads the group.
----------------------------	--

The report also highlighted the existence of the Essex Engagement Toolkit⁷: a clear tool (similar to others that are available) which identifies why, how and when engagement with service users should happen. The Essex Engagement Toolkit includes many useful tools and pointers which support the drive towards engagement, which have informed this report throughout.

⁷ The Essex Engagement Toolkit, www.essexengagementtoolkit.org

6. Options for user engagement: what works and what doesn't work?

Practical mechanisms for user engagement

The following table provides a considerable range of practical mechanisms for user engagement. These have been drawn together from a wide range of sources and synthesized in order to minimise, where possible, overlap between the different methods. For each, the typical pros and cons have been highlighted. Where it is particularly relevant or important, the size of groups typically involved in the mechanism, plus an indicative sense of the cost of the approach, are highlighted.

The purpose of the table is to provide an overview of what practical methods are available; the analysis following the table considers a subset of these mechanisms and the views of people in Essex on which they think are / aren't the most effective when it comes to user engagement.

Note: means by which to give information (i.e. the first level of engagement) are not generally included within this table. They include: leaflets, posters, websites, organisation newsletters, exhibitions, mailouts, fact sheets, advertising, media, videos, photography, text messaging etc. Given, however, that 58% of our survey respondents who hadn't given feedback on health or social care services didn't know how to, we shouldn't underestimate the importance of simply giving information⁸.

Table: Practical mechanisms for user engagement				
Method	Which part of involvement continuum	Description	Typical pros	Typical cons
21st Century Town Meetings	Participation	21st Century Town Meetings involve a large number of people (between 500 and 5,000) in deliberating on local, regional or national issues and make use of modern technology, including wireless voting pads and networked laptops. They combine the benefits of small-scale, face-to-face discussions with those of large group decision-making.	<ul style="list-style-type: none">• Combines large number of participants with considered dialogue• Gathers clear and instant information on what participants think about an issue, including demographic data on what different groups feel• The immediacy and scale of the event can energise the participants	<ul style="list-style-type: none">• High cost• Can raise expectations to unrealistic levels if not managed well• Reliant on technology

⁸ Significant work has been done on the topic of access to information, advice and guidance in both health and social care. A comprehensive research report on this topic is available from the Local Government Improvement & Development Agency: LGID (2009), Transforming adult social care: access to information, advice and advocacy. Available online: <http://www.idea.gov.uk/idk/core/page.do?pageId=9454439>

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
Area Forums	Forums for debate	Area Forums are meetings held in a particular locality. Often the meetings are attended by local councillors, together with senior representatives from the local authorities, the Police, Primary Care Trusts and other key local organisations, to debate key topics and answer residents' questions face-to-face.	<ul style="list-style-type: none"> • Encourage openness and transparency around council decisions • Discussions can be tailored to the concerns of local residents • Provide a direct interface between elected representatives and the communities they represent 	<ul style="list-style-type: none"> • Tend to be attended by the 'usual suspects' although many try hard to attract particularly young people and residents from black and minority ethnic communities • Individual workshops may be dominated by one person or particular viewpoint
Citizens' Juries	Forums for debate	<p>Citizens' Juries consist of a small panel of non-specialists, modelled on the structure of a criminal jury. The group set out to examine an issue of public significance in detail and deliver a 'verdict'.</p> <p>Citizens' Juries are particularly appropriate for involving the wider public in decision-making about setting priorities and strategic planning choices. NHS organisations can pose difficult questions, for example on the prioritisation of services, which involve value judgements in reaching a decision.</p> <p>The jury consists of 12 to 16 members of the public, and members are drawn from a cross-section of the local population. The jury meets for several days, during which time it hears evidence from key 'witnesses' – e.g. health service commissioners, service managers, interest groups. Jurors are also able to ask to hear from additional witnesses</p>	<ul style="list-style-type: none"> • High profile demonstration of public engagement • Jurors broadly reflect the characteristics of the wider population, so bring a degree of representativeness. • Jurors participate as citizens, so, in theory they are not direct stakeholders, but seeking the best outcome for local people as a whole. • Jurors are provided with information from a wide range of perspectives, with time to discuss it in detail, and so are able to come to an informed view. • Can provide an informed public view and generate wider public debate 	<ul style="list-style-type: none"> • As with all activities involving a limited number of people, jurors are open to criticisms of being unrepresentative. • Although jurors are drawn from the local population, their views and values may not reflect those of the wider population • Jurors may not be able to articulate their views and concerns. • Citizens' Juries involve a huge amount of resources (estimate about £25,000) in terms of planning (months) and execution. • The jury may not be able to reach consensus on its recommendations • Rejecting the jury's verdict can be problematic

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		<p>identified through the process. After hearing all the evidence, the jury considers the issue in depth before making recommendations to the NHS organisation.</p> <p>Proceedings are commonly open to the general public to attend and listen to, but they are not able to participate. The process is normally facilitated by an independent moderator.</p>		
Citizens' Panels	Forums for debate	<p>A Citizens' Panel is a large, demographically representative group of citizens regularly surveyed to assess public preferences and opinions.</p> <p>Citizens' panels are generally used to build a picture of a community's priorities, or to get a measure of public opinion on a specific issue a health organisation is working on.</p> <p>Panels are generally made up of 1,000 to 3,000 people (depending on the size of the population they represent) and members reflect the demographics of the local community. Membership of the panel is normally for a fixed period, e.g. two years, after which response rates and engagement tend to decline. Three or four times a year, panel members are surveyed, commonly by postal survey, on their views of a particular topic or topics the organisation is working on. Panel</p>	<ul style="list-style-type: none"> Panel members are recruited to reflect the demographics of the local community and can therefore be seen as representative of the views of the wider community. Panels generally involve a larger number of people than other forms of engagement, and their findings therefore, tend to hold more credibility. Due to the complexity of recruiting and managing the panel and analysing its findings, panels are commonly run by external organisations (e.g. MORI), which gives further independence and credibility. 	<ul style="list-style-type: none"> Panels are complex and resource intensive to recruit, maintain and analyse their views. This means they are usually run by external organisations, which can be expensive. Panels have all the disadvantages associated with surveys in general – e.g. more likely to generate quantitative rather than qualitative information, potentially exclude people with literacy problems etc. It can be difficult to maintain the enthusiasm of panel members, leading to a decline in the return rate of surveys.

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		members may be given additional information in advance or alongside the survey to support them to develop a more informed view. Many local authorities have a citizens' panel, which may be used by NHS organisations.		
Complaints analysis	Getting information	Scrutiny of complaints received to identify common themes	<ul style="list-style-type: none"> • Provides high-quality data about existing service • Substantial issues can be identified • Some complaints can be tackled before they become a problem • Good service can be noted and rewarded • New ideas from the public can be passed on and used 	<ul style="list-style-type: none"> • Generally only covers negative feedback • Groups who tend not to complain will be underrepresented • Might be seen by frontline staff as additional work
Conversation cafés	Forums for debate	<p>Conversation Cafés or Open Surgeries are informal dialogue methods which invite people to take part in discussions about topical issues in an informal setting.</p> <p>Conversation Cafés are a way of enabling a large group of people to discuss questions in an informal and creative way. It does this by creating a relaxed, café-type environment, in which people can talk to others in small groups, and move between groups to meet new people and get a fresh perspective.</p> <p>Conversation Cafés normally take approximately 2 hours. To be successful, café consultations really need to involve</p>	<ul style="list-style-type: none"> • You can determine who the most appropriate participants are, for example, this could be people that represent a cross-section of the local population or stakeholders in a particular issue, and could include health professionals. • Conversation Cafés enable participants to both share knowledge and generate ideas. • The use of mixed and changing groups during the course of the event means that participants hear the same issue from different perspectives, developing their own thinking. • Conversation Cafés generate qualitative information from a potentially large group of people. 	<ul style="list-style-type: none"> • It is helpful if the event is run by someone who is experienced in running Conversation Cafés • Conversation Cafés can be expensive, as you will need to pay for room hire and refreshments, as well as the staff time organising them.

Table: Practical mechanisms for user engagement				
Method	Which part of involvement continuum	Description	Typical pros	Typical cons
Deliberative events	Participation	20 people or more. “Deliberative event” is a generic term for dialogue events where the focus is on deliberation. Some deliberative events record/measure what the participants think about an issue having had an adequate chance to reflect and deliberate on the questions at hand.	<ul style="list-style-type: none"> People can shape public policies or plans and feel they have ownership 	<ul style="list-style-type: none"> Requires careful planning and good moderation skills The organisation has to be prepared to devolve some decision-making
Deliberative mapping	Participation	Deliberative mapping involves both specialists and members of the public. It combines varied approaches to assess how participants rate different policy options against a set of defined criteria.	<ul style="list-style-type: none"> The results are considered opinions rather than articles of faith or rash judgement Specialists contribute to the process without dominating Combination of different approaches creates a deep and comprehensible understanding of public priorities. 	<ul style="list-style-type: none"> Difficult to involve large numbers and high in cost and time-commitment. The results of the process can be contradictory views that leave decision-makers without clear guidance. Very few people have practical experience of running this kind of process.
Electronic discussion groups	Forums for debate	<p>A range of techniques that aim to impart, exchange and receive information electronically. They can be used to target existing patient and carer groups, interest groups and support groups or set up for a specific purpose.</p> <p>Blogs are online journals or noticeboards where people or organisations can provide commentary and critique on news or specific subjects such as politics, local events or health matters. Some blogs function like personal online diaries.</p> <p>Online forums are web tools that allow</p>	<p>Blogs:</p> <ul style="list-style-type: none"> Open and transparent, although often anonymous. Allows anyone to contribute and in their own time. Allows different views to be aired and discussed. Some bloggers have become famous in their own right. Engages people that may not normally be involved in face-to-face consultations. 	<p>Blogs:</p> <ul style="list-style-type: none"> There can be offensive, personal, pointless and inappropriate comments written in response to blogs. Content may need to be moderated. People may need to be encouraged to contribute to the website and post their comments. Blogs rarely allow people to participate actively beyond responding to existing posts

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		<p>discussions to be held online. They allow participants to post their own comments online, which distinguishes them from one-way communication tools such as email bulletins.</p> <p>Webchats are based on the concept of instant messaging. This is a new and informal way to gather information from different stakeholders and to answer specific questions they may have. Participants are invited to contribute to the discussions, but normally anyone can observe the proceedings online even if they cannot contribute.</p>	<p>Online forums:</p> <ul style="list-style-type: none"> • Participants can access it at any time • Anonymity of internet can help people feel comfortable stating their views • Feedback can be gathered quickly • Online forums combine the spontaneity of verbal communication with the clear records of written communication <p>Webchats:</p> <ul style="list-style-type: none"> • The discussion between the person answering questions and the stakeholders or general public is in 'real time' - there is little or no delay in responses. • The discussion is structured but the person answering the questions could participate in more than one webchat simultaneously; • The discussion can be aimed at appropriate participants • The webchat can be publicised on the normal website and the discussions can be left posted on it. 	<p>Online forums:</p> <ul style="list-style-type: none"> • Limited deliberation on online forums, many people just post their comments and do not engage with what others have said • Limited to those with internet access • Can be difficult to get people to post • Requires moderation - un-moderated Online Forums are often chaotic but anonymous and unaccountable moderators can also frustrate participants <p>Webchats:</p> <ul style="list-style-type: none"> • Users expect a fast response from those answering the questions that may not always be possible. • The webchats may not have any direct policy input even though participants are discussing directly with a relevant person

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
			<ul style="list-style-type: none"> There is a sense of the webchat being an event and more personal than other online forums. 	
ePanels	Getting information	ePanels are a way for councils or other organisations to carry out regular online consultations with a known group of citizens.	<ul style="list-style-type: none"> Can be run alongside traditional offline activities and their strength is seen to be as a way of increasing participation in local democracy, particularly amongst young people or those who are time poor. Enables local authorities to reduce their administrative costs - no paper questionnaires or postage is required, there are limited additional costs to run a focus group or live chat (just the cost of online facilitators), data input is not necessary and analysis is generally quicker and can be immediate depending on the type of e-consultation being used. Open and transparent, although often anonymous. Allows anyone to contribute and in their own time. Allows different views to be aired and discussed. Engages people that may not normally be involved in face-to-face consultations. 	<ul style="list-style-type: none"> As with all online methods, there is the potential that ePanels don't encourage the participation of those people without ready access to the internet. If too much is asked of participants – such as too many follow-up emails from ePanels – then this can lead to alienation from the process, and calls for responses may be ignored.
Focus groups	Forums for debate	Focus groups are guided discussions of a small group of people. They are normally one-off sessions, although several may be run simultaneously in different locations.	<ul style="list-style-type: none"> Allows you to identify a framework for discussion, whilst providing freedom for participants to contribute the content. Useful for providing an overview of 	<ul style="list-style-type: none"> Generally involve only a small number of people relative to the wider target population, so are not good for gathering quantitative

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
			<p>issues and identifying issues to be explored in more detail or with a greater number of people later.</p> <ul style="list-style-type: none"> • Good way to explore issues in depth and get qualitative data. • Interaction between participants may generate further thinking and ideas. • Facilitator can ask for responses to be clarified or seek further information in particular areas as issues emerge. • Can be an empowering and learning experience for participants. • Can bring similar people together and help in forming an on-going group for consultation and involvement. • Good way to involve those who cannot read or write, wish to communicate in languages other than English, or have other communication needs. 	<p>information and are open to the criticism that participants' views are unrepresentative.</p> <ul style="list-style-type: none"> • Resource intensive to set up, run, analyse and report on. • Confidentiality harder to ensure. • May generate a large amount of information that, due to the more flexible approach, is not directly comparable across groups. • Requires a skilled facilitator to ensure everyone is enabled to participate fully.
Forum theatre	Forums for debate	Forum theatre is an interactive form of theatre that encourages audience interaction and explores different options for dealing with a problem or issue. This technique is used to work with socially excluded and disempowered groups.	<ul style="list-style-type: none"> • Combines high quality, innovative and interactive theatre with social objectives. • Acts as an ambassador for the arts in the social sector. • Provides an entertaining and meaningful way for working with socially excluded groups. • Challenges established perceptions. • Powerful tool for exploring solutions to difficult problems • Develops skills of the actors, whom are often people for socially excluded groups. 	<ul style="list-style-type: none"> • Forum theatre requires the skills and ability amongst the organisers to create a powerful and meaningful play. • Forum theatre requires actors with the skills to improvise around the audience participation. • Forum theatre is rarely linked directly to decision making.

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
Health panels	Participation	Health panels have primarily been used to explore people's views on 'live' policy issues and the allocation of health service resources. Participants are usually recruited using a quota sampling technique to reflect the socio-economic make-up of the area. Membership is refreshed on a regular basis.	<ul style="list-style-type: none"> • Panels are made up of people recruited for their characteristics in terms of age, gender, ethnicity and location of residence, rather than their particular interests or knowledge about health issues, and represent a cross-section of the population. • Complex issues can be discussed and deliberated by people in an informed way. • Panels can provide useful views on resource allocation and priorities between treatments. • Panels receive relevant information beforehand to enable them to give reasoned and informed opinions. • Taking the views of panels into account when making decisions can help to demonstrate accountability. • Panels can meet at regular intervals, which helps develop a dialogue with local people. 	<ul style="list-style-type: none"> • The information given to panel members is drawn up by professionals, who can only anticipate the type of information needed from their own perspective. • It may be unknowingly selective or inadequate. • If too many issues are discussed there may be insufficient time to allow much debate and panel members may end up just giving their views, rather than the reasoning behind them and developing their own thinking. • The success of the panel discussion is heavily dependent on the skill of the facilitator. • Panels do not provide quantitative information because the number of people taking part is too small.
Interviews	Getting information	<p>One-to-one interviews can be conducted face-to-face or on the 'phone.</p> <p>Semi-structured interviews allow for more qualitative information, and aim to get feedback or explore and issue and enable interviewees to express their own</p>	<ul style="list-style-type: none"> • Possible to get a good cross section of the population and reach specific groups e.g. by using interviewers who speak community languages. • Semi-structured interviews provide a framework for discussion and freedom to explore people's views in more 	<ul style="list-style-type: none"> • Expertise is needed in preparing the questions. • Setting up interviews can be time consuming. • Without significant investment of resources, the number of people

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		<p>feelings and concerns.</p> <p>Structured interviews can be used to get quantitative data, but are less flexible for getting qualitative information, as they do not provide an opportunity for users' views and perceptions to be explored in any detail. Their findings are easier to analyse than those from semi-structured interviews.</p>	<p>detail.</p> <ul style="list-style-type: none"> • Can specifically target the characteristics of people you want to interview. • May involve people who would find it difficult to attend an event or feel inhibited speaking in a group • Independent view can be achieved by using external organisations to do the interviewing. • Response rate can potentially be improved by using community organisations –although beware of potential bias in the reporting. 	<p>interviewed is likely to be comparatively low, so findings are open to criticism that they are not representative.</p> <ul style="list-style-type: none"> • Analysis of findings from semi-structured interviews is time consuming and requires skill. • Some client groups may necessitate the interviewer to be chaperoned or have CRB clearance.
Mystery shopper	Participation	<p>Mystery shopping is a way of auditing services through the involvement of trained user volunteers. Mystery shoppers have been described as 'under cover' service users.</p>	<ul style="list-style-type: none"> • Mystery shopping can help to assess the customer care aspect of services. • As real patients are not involved, there are no confidentiality issues. 	<ul style="list-style-type: none"> • This method can't be used when mystery shoppers would have to display symptoms or be prescribed medication for their conditions. • Mystery shoppers are not generally able to explore an issue in-depth. • Mystery shoppers do not necessarily bring expertise or experience of a service as a user.
Online consultations	Getting information	<p>Online consultations utilise the internet to ask a group of people their opinion on an issue (typically a policy in the development stages). An unlimited number of participants can be sent information about the subject or</p>	<ul style="list-style-type: none"> • Allows a large number of people to contribute • Gives all participants an 'equal voice' • Can reach people who are unlikely to respond to traditional engagement methods 	<ul style="list-style-type: none"> • If not carefully planned, online consultations can generate unmanageable amounts of material • Excludes people who do not or cannot access/navigate

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		download it online and respond via email or comment on a website.	<ul style="list-style-type: none"> • A quick and accessible mode of engagement from the participants' perspective • Allows participants to discuss an issue at their convenience (regardless of location or time); • Anonymity of online processes can encourage open discussion; 	<p>the internet</p> <ul style="list-style-type: none"> • The technology can shape the process rather than vice-versa; • Written communication can be a barrier for some already marginalised groups; • Any perceived complexity, such as registration, can be a barrier to participation
Open space	Forums for debate	<p>Open space events are a large group event (15 people upwards), where participants themselves create their own programme around a pre-determined theme. Apart from the theme, there are no speakers and no set agenda, so participants decide exactly what is discussed and when.</p> <p>Open space events are generally run over one to three days, although it is possible to run shorter versions.</p>	<ul style="list-style-type: none"> • Open space events can generate ideas and thinking completely determined by participants. • Open space events can accommodate a large number of people. • Open space events work well with a diverse range of participants, in terms of background – e.g. health professional or other stakeholder – demographics and other characteristics • Participants only need engage in discussion areas that interest them, hopefully ensuring that they are fully involved, rather than disengage at different points during the process. 	<ul style="list-style-type: none"> • Although the theme is pre-determined, it is impossible to predict the areas of discussion that will be generated participants, therefore some areas may be left unexplored. • Open space events can be complex to manage on the day.
Patient diaries	Getting information	These techniques invite participants to capture and record their experience of health services in a way that can be fed back to staff. Staff discuss the insights obtained and work with participants to make improvements. The techniques can be used in a variety of ways – from being	<ul style="list-style-type: none"> • Over time, involving people in keeping diaries can help to develop a relationship of trust. • Diaries record events and feelings as they happen. • The use of guide questions enables you to explore the issues you are 	<ul style="list-style-type: none"> • The person completing the diary will usually feel they have invested a lot of time and effort and will want to see some clear actions resulting from it. • As completion of the diary is

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		a means of getting information through to being a vehicle for working in partnership	<ul style="list-style-type: none"> interested in. The diary approach provides qualitative information, allowing patients and carers to reflect, explain and suggest ideas and solutions. 	<ul style="list-style-type: none"> unsupervised, responses to the guide questions may stray away from the point. Diaries can be very time consuming to analyse. Those who have literacy problems may not be able to take part.
Public meetings	Forums for debate	A meeting for which there has been an open invitation. There may be a set agenda or discussion may focus on issues raised at the meeting. In the past, public meetings have tended to be used as a method of giving information, but may not be the best way to do this. They can be used creatively to get information from participants or as a forum for debate.	<ul style="list-style-type: none"> Opportunity to reach a wide range of people, and potentially everyone with an interest in the issue to be discussed. Enhances accountability, as the public can directly challenge those responsible for decision-making. Can combine information giving with discussion. 	<ul style="list-style-type: none"> Public meetings are resource intensive, in terms of staff time planning and running them, and costs associated with publicity, venue hire, and refreshments. Unless well promoted, or debating a controversial issue, there may be a low turn-out. Participants are not generally required to book in advance, so numbers are unknown until the day, making the design of the session harder. As participants are not generally required to book, you have no control over who attends, and those attending may be unrepresentative. The event may only attract interested parties, lobby or

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
				<p>pressure groups.</p> <ul style="list-style-type: none"> • There is the potential for interest groups to 'hijack' the meeting with their particular issues or views. • A single meeting is rarely sufficient, as no one day, time or location will suit everyone.
Seminars	Forums for debate	<p>Seminars are discussion groups that aim to impart, exchange and receive information and views. There is normally much greater input from the facilitator than in a focus group, and participants may well include a mixture of professionals, public and patients. Depending on the design – for example, you might include group working, as well as plenary discussions – seminars can accommodate a range of numbers of people.</p>	<ul style="list-style-type: none"> • There is an opportunity to put across information to inform the debate, so can generate informed discussion. • Participants may come from mixed backgrounds – e.g. health professional, service manager, service user – so will have a (rare) opportunity to hear views from others' perspectives. This can potentially lead to more informed discussion and thinking. • Provides qualitative information about people's views. • Existing groups with an interest in the issues to be discussed are likely to find this process engaging and rewarding. 	<ul style="list-style-type: none"> • Generally involve only a small number of people relative to the wider target population, so are not good for gathering quantitative information and are open to the criticism that participants' views are unrepresentative. • Resource intensive to set up, run, analyse and report on. • Confidentiality harder to ensure. • Requires a carefully planned programme and skilled chair / facilitator to ensure everyone is enabled to participate fully.
Surveys and questionnaires	Getting information	<p>Surveys include a group of techniques that measure the opinion of a sample of people. Depending on the particular technique employed, quantitative or qualitative data or a combination of both will be obtained. Techniques can include:</p>	<ul style="list-style-type: none"> • You can potentially gather data from large numbers of people • Can be used to target particular groups • Can be used to give information at the same time 	<ul style="list-style-type: none"> • The questions are determined by those designing the survey, and can omit issues of major concern to people • Findings are not in-depth as

Table: Practical mechanisms for user engagement

Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		<ul style="list-style-type: none"> • Self-completed questionnaires • Online surveys • Telephone surveys 	<ul style="list-style-type: none"> • You can design a sampling framework to survey a representative sample • Findings can be easier to analyse as the questions (and potentially the responses) are clearly defined • Findings provide quantitative data on how many people hold a particular view or prefer a particular option • Questionnaires are quick and easy for people to complete, and do not need to be supervised or completed on-site • You could use a professional organisation to do the work, which would give more independence • Relatively cheap 	<p>there is no opportunity to explore issues, ideas or experiences further</p> <ul style="list-style-type: none"> • People are less likely to complete questionnaires and questions that seek more qualitative data • Questionnaires are unsuitable for people who have problems with literacy, for example, people with learning disabilities, and people who do not speak English as a first language • Depending on how questionnaires are distributed and targeted and the response rate, findings may be unrepresentative of your wider target population • The NHS uses this format often and you need to ensure you are not duplicating work already underway as there is the chance of 'survey fatigue' with recipients
User groups	Participation	User groups are groups of service users that meet regularly to discuss the quality of a service and other related topics. The forum has a recognised mechanism for feeding into the decision-making of a project or service. User forums involve longer-term engagement with people who	<ul style="list-style-type: none"> • By definition, members of the group use the service and therefore bring some experience and / or expertise in the issues. • Because the meetings are on-going basis, you can build a positive 	<ul style="list-style-type: none"> • Service users on the group may be unrepresentative of the views of wider service users. • A service user forum cannot capture the views of

Table: Practical mechanisms for user engagement				
Method	Which part of involvement continuum	Description	Typical pros	Typical cons
		are key stakeholders and generally well-informed about the issues and service available. They help to identify the concerns and priorities of other service users and can lead to the early identification of problems or ideas for improvements.	<ul style="list-style-type: none"> relationship with the forum members. Because forum members are involved on an on-going basis, they can develop additional expertise in the issues. 	potential users who are for some reason unable or unwilling to access the service.
World Café	Forums for debate	World café is a method that makes use of an informal café for participants to explore an issue by discussing in small table groups. Discussion is held in multiple rounds of 20–30 minutes with a plenary at the end of the event.	<ul style="list-style-type: none"> Creative process for developing new ideas Informal and inclusive Has the potential to be cheap and easy to organise 	<ul style="list-style-type: none"> Requires a clear and relevant question Cannot be used to make direct decisions

People's views on the most effective mechanisms for user engagement

In the context of this work, people engaged by this research were asked to give their views on a subset of the available techniques.

This subset was chosen as being representative of the general mechanisms available. For example, “surveys” can be taken to mean any of the more detailed options described in the table above. The subset was also chosen on the basis of those techniques which are more likely to be realistic within the context of HealthWatch Essex's remit (see Section 1. Though it would have been preferable to ask people to consider every potential mechanism, the scale of the work (as highlighted in Section 2) meant that such choices needed to be made.

The following table combines the quantitative and qualitative results of people's views on each of the engagement mechanisms in order of most popular to least popular.

Table: People's views on effective mechanisms for user engagement			
	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?	Focus group views: qualitative comments	Focus group view: at a glance

Answer Options	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
Surveys – Measure the opinion of a sample of people, and can be carried out in various different ways	3	5	19	<p>On balance, surveys were the most popular form of engagement with the people involved in this work. Interestingly, people engaged tended to assume that surveys would always form part of any engagement, and so concentrated on second order issues. These included:</p> <ul style="list-style-type: none"> • Ensuring surveys are done independently to minimise leading questions • A clear preference for online or paper-based surveys, and definitely not for telephone surveys • The need to pitch the length of surveys right so as to not put people off taking part • Concern over response rates • Concern over cost • The importance of feedback 	Yes (5)
Focus Groups – Guided discussions of a small group of citizens on particular topics	4	4	19	<p>There was overwhelming support for focus groups. The two defining reasons for this were that it was small enough to be able to (1) share a true opinion, and (2) engage in detail in a particular topic.</p> <p>Some caution should be attached to this finding in the focus groups, since by definition people who attended the focus groups were (generally) comfortable and used to such an approach. However, the quantitative findings also indicate this is one of the most popular approaches considered.</p>	Yes (5)
Area Forums – Meetings held in a particular local area	2	7	18	<p>Although there was a small minority of people who were sceptical about Area Forums, most people found the ideas of these attractive. They felt people were more likely to be engaged through Area Forums since people are generally better connected and knowledgeable of their local community, and therefore “closer” to the issues discussed.</p> <p>One potential downside to this engagement is that people may express stronger views, or that a small number of voices would</p>	Yes (4)

Table: People's views on effective mechanisms for user engagement

Answer Options	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?			Focus group views: qualitative comments	Focus group view: at a glance
	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
				<p>dominate proceedings. Such issues it was felt should be proactively managed.</p> <p>Preparation and focus were thought to be key to Area Forums, both on behalf of people and senior officials. Good to have regular access to senior officials. There was a slight concern that senior officials involved may be ticking a box by attending and do nothing as a result, though suitable feedback and accountability mechanisms were felt to potentially address this.</p> <p>Area Forums were noted to be a particularly good approach in terms of rural locations.</p>	
Citizen's Panel – Large group of citizens who are surveyed three or four times a year	2	5	20	<p>Views were mixed on Citizen's Panels. People felt that this form of engagement could be useful, as long as participants were well briefed and prepared.</p> <p>Feedback was an important issue: there were concerns that the views expressed through such Citizen's Panels may not be made known more widely; knowing what was done with the views also expressed was considered important. There were also concerns that such an approach would need to be suitably representative.</p>	Maybe (3)
Seminars – Discussion groups that aim to impart, exchange and receive information and views, including a mixture of people	4	4	19	<p>Those who had experienced seminars had found them to be useful. More generally, though, people felt that seminars represented a way of giving information people on which they could then later base their views and engagement.</p> <p>Some people felt that seminars would be too formal and could be</p>	Maybe (3)

Table: People's views on effective mechanisms for user engagement

	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?			Focus group views: qualitative comments	Focus group view: at a glance
Answer Options	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
				too intimidating an environment in which to share views or engage with any debate.	
Social media – Range of software programs used via the internet, where content is mainly created by users	2	8	17	<p>A large majority of people considered social media to be a key part of engaging people. This was for several reasons. First, it enables a large number of people to get involved. Second, it is cheap, or even free (particularly for users). Third, it enables a large array of views and perspectives to be put forward. Fourth, it breaks down “power” barriers, so that people could potentially have direct access to decision makers (and vice versa). Fifth – and perhaps most importantly – it is something that is increasingly embedded in people's everyday lives, and so doesn't require much additional effort by people to be engaged.</p> <p>Typical problems with such engagement mechanisms were highlighted, such as access and privacy issues. More specifically, a question was raised over the quality of information available. However, people felt that – with appropriate moderation, or even direct involvement from, for example, the local authority – this could be overcome, or at least minimised.</p>	Yes (4)
Online Forums – Enables discussions to be held online	4	6	17	<p>Online Forums gave rise to the most divergent views we received. Some people felt they were an excellent way of engaging people; others felt they were the very worst way possible to engage people. This perhaps reflects the fact that Online Forums have existed for some time, such that the pros and cons of them are better known than for other mechanisms.</p> <p>Beyond the issues that were always likely to be highlighted –</p>	Maybe (3)

Table: People's views on effective mechanisms for user engagement

Answer Options	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?			Focus group views: qualitative comments	Focus group view: at a glance
	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
				<p>access, anonymity, lack of internet access – the key point people noted was that any discussion within an Online Forum must have structure, stimulation and moderation (and thus are similar to “real world” forums.</p> <p>People acknowledged that online activity is increasing, and recognised that Online Forums could form a part of that. When asked to express a preference, though, many opted for social media as a better means of engagement.</p>	
Conversation Cafes – Informal drop-in discussions in public places	6	10	11	<p>The informality of Conversation Cafés was attractive to the majority of people. In particular, the fact it would give rise to a safe environment to share view, enable opportunities for peer support, and provide opportunities for social engagement will all be considered positively.</p> <p>The majority of people recognised that Conversation Cafés could be good for people rather than a collective voice. This was particularly noted in being in a position to raise issues of personal concern and receiving instantaneous feedback.</p> <p>The informality also led to concerns of keeping records of conversations or decisions made. As a result, people were concerned the informality may not lead to meaningful change.</p> <p>Finally, practical issues of access and knowing when and where these were taking place were a concern for people. There were also more significant worries about ensuring privacy (if required)</p>	Maybe (3)

Table: People's views on effective mechanisms for user engagement

	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?			Focus group views: qualitative comments	Focus group view: at a glance
Answer Options	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
				in an informal environment.	
World Café – Explore an issue by discussing different parts of it in small table groups, moving every 20-30 minutes	10	8	9	<p>The World Café approach was felt to present a good networking and social opportunity for people – something they considered valuable. It was also identified as an opportunity to find out – through organisational presences – what support is available. People felt it was good to have a chance to meet in a big group, but then go into small groups. This was especially since it would give them chance to explore different aspects of an issue</p> <p>Since this approach is more structured than other Café formats, people found it more attractive, whilst recognising the need for good organisation and facilitation.</p> <p>Many of the practical issues highlighted in the analysis for Conversation Cafés were also mentioned here.</p>	Yes (4)
Citizens' Jury – A small panel of non-specialists, who set out to examine an issue of significance in detail and deliver a "verdict".	8	8	11	<p>In general, people were opposed to the idea of using a Citizens' Jury for the purpose of engagement. They felt the environment it would create would be the wrong one, and could be a very exclusive way of capturing views.</p> <p>There was, however, one notable circumstance in which people felt a Citizens' Jury was appropriate: if one was set up to inform, or indeed decide on, a new service that is to be introduced or an existing service that is to be significantly altered or closed. In this context, people felt a Citizens' Jury would be well-suited.</p>	No (1)
Forum Theatre – Interactive theatre that	9	8	10	The innovative nature of the Forum Theatre approach was appreciated by people in general. As a result, though, it sharply	No (2)

Table: People's views on effective mechanisms for user engagement

	Quantitative comments (taken from survey): How strongly do you feel each of the following processes should be made available?			Focus group views: qualitative comments	Focus group view: at a glance
Answer Options	1 – Definitely or probably shouldn't be available	3 - Indifferent	5 – Definitely or probably should be available		Yes / Maybe / No (Quant scale)
encourages audience interaction and explores different options for dealing with a problem or issue				<p>divided opinion, with the majority strongly feeling it wasn't a suitable approach.</p> <p>Many felt it could be a patronising way of engaging people. They also recognised that, though attractive initially, the approach could be short-lived and could have been relatively expensive. They also questioned how useful the feedback / information received would be for decision makers.</p> <p>Those who did find it interesting noted that it could be useful to support peer-led engagement, particularly for people with learning disabilities or young people. More generally, whilst recognising the limited impact for "hard" feedback, it could provide "soft" feedback in areas such as people's attitudes.</p>	
Open Space events – Participants themselves create their own programme around a pre-determined theme. No set agenda, no set speakers	16	0	11	<p>Open Space events were by far the most unpopular engagement mechanism of those considered. Most typically, people felt they would result in "chaos" and far less personal than any of the other engagement mechanisms.</p> <p>A small minority thought Open Space events could present an interesting / fun opportunity, but most were worried that such an approach would be "hogged" by people with their own agendas.</p>	No (1)

Discussion on effective mechanisms for user engagement

The table above has one defining characteristic: people were generally favourable about the types of engagement mechanisms they might already know about and are familiar with.

With all the caveats that could be anticipated about different types of engagement (e.g. internet access for mechanisms like social media and online forums), people expressed clear preferences for surveys, focus groups, area forums, citizen's panels, seminars, social media and online engagement. For those other suggested mechanisms, people had quite definite reservations beyond the issues typically raised.

There are some important caveats to stress:

- Area Forums present a real opportunity for engaging people at the level of their local communities; however, significant effort would need to be put into these to address the two main concerns people highlighted: (1) strong / overbearing voices; and (2) knowing the engagement was meaningful. Significant thought would also need to be given by what is meant by "Area". There was a clear preference, though, that areas should be based on geography rather than an area of interest (e.g. impairment-specific meetings, service-specific meetings)
- Citizen's Panels could be a significant boon to engagement; however, questions of representation would need to be regularly considered and addressed to ensure their findings are credible
- Seminars may more usefully be thought of as an effective means of giving information, rather than getting it.

Of those mechanisms that people didn't consider effective, there are also additional points to make that means ruling some of them out may be premature. In particular, the concept of Cafés themselves – either Conversation Cafés or World Cafés – wasn't ruled out. The primary issue here was one of practicalities which, with good coordination and communication, can be overcome. Furthermore, Citizens' Juries weren't in general considered useful, except in that key stage of the commissioning cycle when new services are being planned or existing services are being considered for significant restructure or closure.

A more general observation can be found in a division between older and young people when it came to using online and social media. Some were frustrated with the assumption that everyone could use a computer or had internet access, meaning there were no alternative or accessible contact methods for them. On the other hand, for some who did use online technologies, these were often a method for overcoming impairment-related barriers. For example, one young man who had speech difficulties preferred online forums because he felt it stopped people judging. On this point, it's useful to note that 61% of people found out about the survey via online methods, 16% via "traditional" methods (i.e. paper-based) and the rest via word of mouth.

One common theme highlighted by people of all the mechanisms, no matter how popular they were, was of effective facilitation. It would not be too simple a summary to say effective facilitation is a necessary foundation for effective engagement.

Finally, the question of independence was often raised by participants: they want to be reassured that the outcome of the engagement hasn't already been determined and their engagement is a means by which that conclusion is justified. Nevertheless, our survey indicates that people can see the need for different types of organisation to collect views at different times:

Who do you think should be responsible for collecting your views and lived experiences? (Please tick all that apply)		
Answer Options	Response Percent	Response Count
Officers from Essex County Council	56%	15
Health system managers (such as people who work as managers in hospitals)	59%	16
People who work for HealthWatch	56%	15
People who work for voluntary sector organisations	52%	14

Independent consultants	19%	5
Other users / patients	59%	16

Only independent consultants were considered the least appropriate for collecting views.

One significant implication of this table for HealthWatch is the need for it to determine and communicate a unique “offer” to people in the work it does. Where people didn’t easily differentiate between the different types of people who should be responsible for collecting views – such as between ECC, health system representatives, voluntary sector representatives – so HealthWatch Essex needs to ensure people understand why they would specifically share particular types of feedback or experience with HealthWatch Essex representatives.

7. Conclusions and recommendations

Rather than replaying all of the above findings, this section highlights the main conclusions to be drawn from the research analysis. These conclusions should be read in conjunction with the recommendations below.

There is a considerable range of mechanisms for enabling people to engage in developing the health and social care system.

There are 3 fundamental issues, though, that mean engagement is currently limited:

- (1) People don't typically engage in shaping health and social care systems, in the same way they aren't engaged in public service delivery or reform more generally
- (2) Our research suggests that a significant proportion of people (58%) aren't even aware of the ways in which they can share their thoughts and views on health and social care should they wish to
- (3) Even when they are used, the majority of existing mechanisms for engagement are not being used as well as they could be, neither by commissioners or by individuals.

The majority of people are motivated to share their views because of a personal, almost always negative experience as a user of health or social care services. Building on a general feeling that feeding back on their specific case might help people more generally, the sense of an individual providing feedback was often a precursor to wider thought about collectively improving health and social care systems.

Of the reasons why people don't engage, the most significant was the question of whether engagement was meaningful. People either felt that they were being listened to as an exercise or, if they were listened to, that little might happen as a result. This was followed by the sense that contributing a view wouldn't make any difference.

Most people understood, though, the limitations for acting upon advice received through engagement. Overall, acknowledgement and explanation of the issues raised was more important for most as a result of the process of engagement. For others, knowing their feedback had made a difference or effected a change was what mattered most.

When considering which mechanisms they preferred for engagement, people were generally favourable about the types of engagement mechanisms they might already know about and are familiar with. With all the caveats that could be anticipated about different types of engagement (e.g. internet access for mechanisms like social media and online forums), people expressed clear preferences for surveys, focus groups, area forums, citizen's panels, seminars, social media and online engagement. For those other suggested mechanisms, people had quite definite reservations beyond the issues typically raised.

This result may be a function of the research itself: given we primarily used focus groups and surveys, it shouldn't be surprising that focus groups and surveys were identified as popular methods. However, people *did* express interest in other methods, and generally understood the different value of these for different occasions.

One common theme highlighted by people of all the mechanisms, no matter how popular they were, was of effective facilitation. It would not be too simple a summary to say effective facilitation is a necessary foundation for effective engagement.

One significant implication of our findings for HealthWatch Essex concerns who people felt should seek their views on health and social care. People didn't easily differentiate between the different types of organisations who should be responsible for collecting views – such as between ECC, health system representatives, voluntary sector representatives – so HealthWatch Essex needs to ensure people understand why they would specifically share particular types of feedback or experience with HealthWatch Essex representatives.

Recommendations

The recommendations below flow from the key points found as a result of this work, in terms of both (1) the context within which engagement happens (general recommendations), and (2) the practical ways in which people in Essex want to be engaged with (practical recommendations). In both set of recommendations, however, and reflecting the unique opportunity available to HealthWatch Essex, it is suggested they take specific responsibility.

The nature of the recommendations is designed to be practical and achievable. They are thus specific, if not always in detail then in intent.

- HW1. As a minimum, we would recommend the creation of an action plan – or relevant part of HealthWatch Essex's first business/operations plan – to address the recommendations made within this report.
- Where recommendations are not taken forward, an appropriate communication explaining the reasons for this would help demonstrate a clear, refreshed commitment to meaningful engagement in Essex.
- HW2. Given that 58% of our survey respondents who hadn't given feedback on health or social care services didn't know how to, the provision of information is a fundamental cornerstone for developing people's engagement in the health and social care system
- An evaluation or review of how this currently happens, why it isn't working and what should be done about it should be considered as a significant early contribution that HealthWatch Essex could make
 - There should be a significant promotion of <http://www.engageessex.org.uk/> in general, and developing a subsite for health and social care in particular. This should include both current and upcoming consultations, as well as more general opportunities for engagement
 - A full list of different opportunities for engagement – reflecting the involvement continuum – should be made available and regularly updated
 - The Essex Engagement Toolkit should be widely promoted, especially to relevant organisations across Essex
- HW3. Information on how local authorities have or haven't used views gathered through engagement used should be routinely published following the relevant engagement and decision points
- More specifically, any feedback received from a person through engagement should at the very least be acknowledged
- HW4. There should be an update on each of the recommendations from ECC's most recent work on user engagement. Where action is required, this should be captured in a dedicated project plan. The recommendations were as follows:
- User engagement needs to be planned into projects, and undertaken at an earlier stage of the commissioning process
 - A strategy to engage with seldom heard groups is required, and needs to coincide with similar efforts across ECC
 - Greater use should be made of community-based, local engagement mechanisms
 - There needs to be a much greater use of online user engagement
 - Engagement methods need to be flexible enough to adapt to the commissioning process
 - User engagement could be enhanced by greater work with health and other partners
 - There needs to be a tool to evaluate user engagement mechanisms
 - User engagement success needs to be highlighted to demonstrate its value.
- HW5. Wider links with both the Right to Control Trailblazer and the Community Budgets pilots should be explored. The engagement mechanisms and learning from both of these programmes will be of benefit to HealthWatch's work and that of health and social care, and vice versa.
- HW6. A dedicated budget – either a fixed amount, or proportion of the relevant budget – should be allocated to enable meaningful engagement
- HW7. A full involvement policy should be developed in coproduction with users and signed up to by relevant agencies. As well as setting out the purpose and principles of such a document, this involvement

policy should agree consistent payment terms for different types of engagement. It should also provide a definitive and consistent statement on meeting travel / carer / access etc. costs

- HW8. Accessible formats of engagement documents should be made available on request. More generally, the relevant bodies should liaise with impairment- or equality-specific groups to utilise their expertise in engaging relevant groups
- HW9. HealthWatch Essex should develop its unique “offer” and promote this – both to all people in Essex *and* to health and social care commissioners – in order to establish its specific role within the health and social care economy
- HW10. Surveys and focus groups
- a. ECC / HealthWatch Essex should commit to commissioning a series of surveys and focus groups on a range of specific topics that will support its work
 - b. These should comprise paper and online surveys (not telephone surveys)
 - c. The surveys themselves should be coproduced
 - d. Findings from surveys should be shared publicly, and directly with each person who took part
 - e. Focus groups should be on particular topics
 - f. At least one of these should be in response to “bottom-up” issues identified by people in Essex. This could be achieved in one of two ways:
 - i. Specifically engage with people to find out what topic they would like to be engaged on (perhaps using a longlist in the first instance, with an “other” option)
 - ii. Analyse comments and complaints and identify a longlist of issues that emerge from this analysis
 - g. Focus groups should be facilitated, preferably by someone independent of ECC / HealthWatch, but with presence from both
- HW11. Area Forums
- a. The potential for Area Forums should be explored. This exploration should begin from the basis that Area Forums should exist, reflecting the preferences expressed by people so far
 - b. These explorations must include how best to ensure effective facilitation so that everyone who attends such Area Forums feels enabled and confident to contribute
 - c. Senior local officials from all relevant organisations – including health and social care bodies – must be suitably prepared and trained to value such Area Forums
 - d. Though people engaged in this research didn’t specifically comment on what these “areas” should be, we suggest that they should be developed in collaboration with the Health & Wellbeing Board and draw upon the findings of the latest JSNA
- HW12. Citizen’s Panel
- a. An independent and expert organisation – with experience of running Citizen’s Panels or similar – should be considered for carrying out a feasibility study on establishing and maintaining a Citizen’s Panel in Essex
 - b. Such a feasibility study would need to consider how any Citizen’s Panel was representative of the Essex population, perhaps through a dedicated recruitment process. They should also explore any added benefit that such an exercise would provide to awareness of the work HealthWatch is embarking on
- HW13. Seminar series
- a. A series of seminars, which present a range of speakers – perhaps even those responsible for change in health and social care – should be considered. The purpose of these would be to raise levels of awareness, understanding and engagement with the topic of health and social care, building on the policy interest these issues have given rise to at a national level
- HW14. Citizens’ Jury
- a. The option of a Citizens’ Jury for an appropriately significant piece of work in health and social care should be retained. Options for such topics include: Provision of information; Personal Health Budgets and their implementation; or safeguarding and Quality Assurance
- HW15. Social media and online engagement

- a. There must be a strand of work dedicated specifically to social media and online engagement mechanisms
- b. Such a strand must first focus on addressing access issues associated with these methods
- c. The potential for piggy-backing on existing national initiatives to do this is tremendous – such as Go On UK and UK Online Centres – and should be explored
- d. HealthWatch Essex should have a dedicated presence on all social media sides, particularly Facebook, Twitter and YouTube. These should be separate to any social media profiles existing bodies have (including Essex County Council and health bodies)
- e. Local people engaged also expressed a willingness to share their time and experience of engaging online with those who were less familiar – an offer that should be accepted and acted upon
- f. At least one – and preferably two – HealthWatch officers must have responsibility for social media and online engagement embedded within their job description, person specification and performance objectives

HW16. Training:

- a. Training should be made available for senior professionals in the health and social care systems on the benefits of engagement. This should be underpinned by strong evidence for the effectiveness and benefits of engagement
- b. Given the vital importance of effective facilitation to good engagement, training on how to effectively facilitate should be made available for professionals / officers and for relevant organisations across the voluntary and community sector in particular
- c. In order to address one of the significant personal barriers to engagement, training should be made available for users who would like to be engaged but are not. The training should address the issues highlighted in the personal barriers of Section 3

HW17. The results of this research should be clearly communicated to anyone who took part in it. Furthermore, this research should be made available through HealthWatch Essex

HW18. An Equality Impact Assessment should be carried out on any engagement plans agreed, and the results used to refine those engagement plans, to ensure this work suitably engages all groups of people represented within Essex.

HW19. An independent evaluation of how successful the engagement approach – specifically of HealthWatch, as well as the health and social care systems more generally – should be carried out by October 2014 (i.e. 18 months after the start of HealthWatch Essex).

References

- Department of Health (2008), Real Involvement: Working with people to improve health services. Available online: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalassets/dh_089785.pdf
- Department of Health (2003), Strengthening Accountability: Involving patients and the public – practice guidance. Available online: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalassets/dh_4074292.pdf
- Department of Health (2009), The engagement cycle: a new way of thinking about patient and public engagement (PPE) in world class commissioning. Available online: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098658
- ecdp** (2010), Disabled people in Essex – understanding the demographics: <http://www.ecdp.org.uk/home/2010/4/7/disabled-people-in-essex-understanding-the-demographics.html>
- Essex County Council (2011), Ensuring the Commissioning Process is influenced by User Engagement: Formulating an agreed approach across Adult Social Care
- Essex Engagement Toolkit. Available online: www.essexengagementtoolkit.org
- Health Canada (2000), Policy Toolkit for Public Involvement in Decision Making. Available online: http://www.hc-sc.gc.ca/ahc-asc/alt_formats/pacrb-dgapcr/pdf/public-consult/2000decision-eng.pdf
- Health Foundation (2009), Engaging communities for health improvement: A scoping study for the Health Foundation. Available online: <http://www.health.org.uk/public/cms/75/76/313/597/Engaging%20communities%20for%20health%20improvement.pdf?realName=788I5U.pdf>
- Health Foundation (2010), Community Engagement report
- Health, Social Services and Public Safety (2007), Circular HSC (SQSD) 29/07. Available online: http://www.dhsspsni.gov.uk/hsc_sqsd_29-07.pdf
- Involve (2005), People & Participation: How to put citizens at the heart of decision making. Available online: <http://www.involve.org.uk/wp-content/uploads/2011/03/People-and-Participation.pdf>
- Involve (2010), What the public say: Public engagement in national decision making. Available online: <http://www.involve.org.uk/wp-content/uploads/2011/03/What-the-public-say-report-FINAL-v4.pdf>
- Irish Society for Quality and Safety in Healthcare (ISQSH) (2009), “Now we’re talking”: A practical toolkit for public and patient involvement in healthcare. Available online: <http://www.lenus.ie/hse/bitstream/10147/74413/1/Healthcare%20toolkit.pdf>
- Joseph Rowntree Foundation (2000), Age and change: Models of involvement for older people. Available online: <http://www.jrf.org.uk/publications/age-and-change-models-involvement-older-people>
- Joseph Rowntree Foundation (2006), Making user involvement work: supporting service user networking and knowledge. Available online: <http://www.jrf.org.uk/publications/making-user-involvement-work-supporting-service-user-networking-and-knowledge>

- Joseph Rowntree Foundation (2008), Designing citizen-centred governance. Available online: <http://www.jrf.org.uk/publications/designing-citizen-centred-governance>
- Joseph Rowntree Foundation (2010), Involving users in commissioning local services. Available online: <http://www.jrf.org.uk/publications/users-local-services>
- Joseph Rowntree Foundation (2011), Involving older people in service commissioning: more power to their elbow? Available online: <http://www.jrf.org.uk/publications/involving-older-people-more-power-to-their-elbow>
- LGID (2009), Transforming adult social care: access to information, advice and advocacy. Available online: <http://www.idea.gov.uk/idk/core/page.do?pagelId=9454439>
- NCVO (2011), Pathways Through Participation: What creates and sustains activity citizenship?
- NDTi (2010), A guide to coproduction with older people. Available online: http://www.ndti.org.uk/uploads/files/Personalisation_-_dont_just_do_it_coproduce_it.pdf
- NHS (2007), Armchair Involvement: Practical technology for improving engagement. Available online: <http://www.institute.nhs.uk/images//documents/BuildingCapability/Armchair/armchair%20involvement%20report.pdf>
- NHS (2007), Patient and Public Engagement Toolkit for World Class Commissioning. Available online: <http://www.engage.hscni.net/library/PPE%20Toolit%20-%20South%20Central.pdf>
- NHS (2011), Patient Involvement and Public Accountability: A report from the NHS Future Forum. Available online: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_127544.pdf
- NHS Confederation (2011), Patient and public engagement in the new commissioning system. Available online: http://www.nhsconfed.org/Publications/Documents/PPE_181011.pdf
- NHS Confederation (2012). Patient engagement case studies. Available online: <http://www.nhsconfed.org/Key-Health-Issues/HPD-March2012/Pages/Policy-Developments-summary2-240112.aspx>
- North West Mental Health Improvement Programme (2011), Engagement in the Commissioning Cycle: A Guide for Service Users, Carers, the Public, GP's, Commissioners and other stakeholders in Mental Health Care Services. Available online: <http://www.nmhdu.org.uk/silo/files/engagement-in-the-commissioning-cycle.pdf>
- OPM (2008), Engaging Communities
- Picker Institute (2011), Invest in engagement. Available online: <http://www.investinengagement.info/SiteGuideWhyDolt>
- SCIE (2007), Practice guide: the participation of adult service users, including older people, in developing social care. Available online: <http://www.scie.org.uk/publications/guides/guide17/files/guide17.pdf>

Annex 1 – full quantitative details of engagement

Below are the numbers and demographic details of people engaged directly and indirectly.

Numbers and impairment groups of people engaged

We directly engaged with 121 people in this work through our focus groups and survey. Of these:

- 16% (15) were people with learning disabilities
- 33% (31) were people with physical or sensory impairments
- 17% (16) were people with long-term health conditions
- 11% (10) were people with mental health conditions
- 6% (6) were carers
- 5% (5) were organisational representatives
- 12% (11) were unknown.

We also indirectly engaged or made aware a significant number of people in and of the work as follows:

- 204 full **ecd**p members
- 74 other people who regularly engage with **ecd**p as volunteers or similar
- 193 key stakeholders and affiliate members
- All members of an existing service user reference group, associated with the Right to Control.

More generally we did the following to share news of the work:

- Contacted every CVS In Essex
- Contacted 10 Mind centres across Essex
- Contacted 9 Mencap groups across Essex
- Distributed 600 printed leaflets to **ecd**p **pass** clients
- Distributed 300 leaflets via the Carnarvon House service
- Regularly tweeted to **ecd**p's 1,590 followers
- Regularly posted articles on our website, which averages just over 3,000 unique visitors per month.

Focus groups

In total, 91 people shared their lived experience in person through attending the focus groups at **ecd**p and Age UK Essex.

- Tuesday 27 March at Age UK – 30 people attended
- Thursday 5 April at **ecd**p, facilitated by Rich Watts – 13 people attended
- Tuesday 17 April at Firstsite, Colchester, facilitated by Faye Savage – 16 people attended
- Thursday 3 May at **ecd**p, facilitated by Faye Savage – 17 people attended
- Thursday 10 May at **ecd**p, facilitated by Faye Savage – 15 people attended

The primary impairment breakdown for the focus groups was as follows:

- 23% (14) were people with learning disabilities
- 35% (22) were people with physical or sensory impairments
- 2% (1) were people with long-term health conditions
- 7% (4) were people with mental health conditions
- 10% (6) were carers
- 8% (5) were organisational representatives
- 15% (9) were unknown.

Survey

A total of 30 people shared their views through the online survey. The multiple impairment breakdown for the survey was as follows:

- 5% (1) were people with learning disabilities

- 47% (9) were people with physical or sensory impairments
- 79% (15) were people with long-term health conditions
- 32% (6) were people with mental health conditions
- 11% (2) were unknown.

Further demographic breakdowns

Below are the broader demographic breakdowns of the people we directly engaged with, for whom this information was known.

Gender

- Male – 44%
- Female – 52%
- Prefer not to say – 4%

Sexuality

- Bisexual – 9%
- Heterosexual / straight – 91%
- Homosexual – 0%
- Other – 0%
- Prefer not to say – 0%

Ethnic group

- Asian – Bangladeshi – 0%
- Asian – Indian – 0%
- Asian – Pakistani – 0%
- Asian – Other – 0%
- Black – African – 4%
- Black – Caribbean – 0%
- Black – Other – 0%
- Chinese – 0%
- Gypsy/Roma – 0%
- Chinese – 0%
- Mixed - White and Black African – 0%
- Mixed - White & Black Caribbean – 0%
- Mixed - White and Asian – 4%
- Mixed - Other mixed background – 0%
- White – British – 87%
- White – Irish – 4%
- White – Any other white background – 0%
- Any other ethnic group – 0%
- Prefer not to say – 0%

Area of Essex

- North East Essex – 9%
- North West Essex – 0%
- Mid-Essex – 48%
- South West Essex – 4%
- South East Essex – 9%
- Southend – 17%
- Thurrock – 0%
- Outside of Essex – 13%

ecdp member

- Yes – 54%
- No – 46%

Annex 2: ecdp's lived experience approach

Lived experience is the expertise that all disabled people acquire through their day-to-day experiences of being a disabled person.

Taking a social model perspective, it includes people's experiences of:

- Accessing society as a disabled person and some of the barriers involved
- Managing their impairment
- Achieving independent living.

As a user-led organisation, the voice and lived experience of disabled people underpins everything **ecdp** does. A lived experience approach enables **ecdp** to understand the experiences, perspectives and opinions of disabled people and to aggregate this into a collective voice of disabled people in Essex.

As such, lived experience is a two-way process:

- Disabled people are able to highlight the issues which affect them (ecdp collect lived experience)
- **ecdp** is able to draw on the expertise of disabled people (ecdp invite lived experience)

Mechanisms

As a user-led organisation running a number of services with nearly 4,000 disabled people, we collect on an ongoing basis the lived experience through our day-to-day work. Additionally, we use a number of methods to ensure that the two-way process described above works for disabled people and for **ecdp**.

Lived Experience Log

The lived experience log enables staff across all **ecdp** teams to record the lived experience shared with them by disabled people through their interactions when providing services. The log is analysed on at least a quarterly basis so that trends or themes can be monitored.

Communications

ecdp communicate with members, and invite lived experience, through a variety of different mechanisms that take account of all access requirements. These include:

- Quarterly magazine⁹
- Monthly email bulletin¹⁰
- Our website¹¹
- Dedicated member forum
- Various forms of social media, including Twitter, Facebook, YouTube and Audioboo.

Research

Where issues need to be discussed with members, **ecdp** uses a variety of techniques, including one-to-one methods or focus groups, which enable people to share and debate their opinions on a particular issue with other disabled people.

Online surveys, promoted through the above listed communications, enable **ecdp** to confidentially collect people's lived experience in a way that is both convenient for them and easy for **ecdp** to run.

⁹ **ecdp** magazine: <http://www.ecdp.org.uk/magazine>

¹⁰ **ecdp** monthly email bulletin: <http://www.ecdp.org.uk/bulletin/>

¹¹ **ecdp** website: <http://www.ecdp.co.uk>

All of the above is led by a dedicated Lived Experience Officer role – a role we believe to be unique within User-Led Organisations.

Lived experience in practice

Below are some examples of how **ecdp's** lived experience approach has worked in practice. They demonstrate how our approach has enabled ecdp to understand how disabled people in Essex are affected by particular issues. These examples demonstrate how this approach allows responses and action to be informed by the voice of disabled people themselves.

Welfare Reform – DLA and PIP

Responding to the changes to Disability Living Allowance (DLA) announced in the government's 2010 budget, ecdp launched an online survey, which received 141 responses within 2 weeks and captured disabled people's initial reactions to the proposed reform of DLA and changes to the Independent Living Fund (ILF).¹² This information and further lived experience captured through our lived experience log in the interim underpinned ecdp's response to the government's consultation on DLA reform in February 2011.¹³

Looking towards the implementation of the benefit which will replace DLA, Personal Independence Payment (PIP), ecdp established a reference group of 20 disabled people with a variety of lived experience, including people from different impairment groups and those with different experience of DLA. An online survey, which aimed to understand how people wanted PIP to work when it replaced DLA, and received 50 responses, enabled triangulation of these in-depth discussions with the wider experience of other disabled people in Essex. Contribution to this was promoted through ecdp's traditional and online communications.

This work informed ecdp's responses to government over the summer-long consultation on PIP, a final report submitted in August 2011,¹⁴ **ecdp's** contribution to DWP's PIP implementation development group and the evidence given to the Welfare Reform Bill Committee by ecdp's CEO, Mike Adams¹⁵.

Access to Work

Members highlighted a number of concerns around changes to Access to Work support, which were observed during monthly analysis of our lived experience log. To understand the wider issues, ecdp carried out an online survey, which received 54 responses, and consulted with online communities through a social media approach.

The combined evidence collected formed ecdp's submission to the Sayce Review of specialist disability employment support.¹⁶

In August 2011, the lived experience log mechanism highlighted inconsistent changes being made to Access to Work client's driver support. Consultation through ecdp's social media issues revealed this

¹² **ecdp's** DLA / ILF survey results: <http://www.ecdp.org.uk/home/2010/7/23/results-of-ecdps-survey-on-dla-ilf.html>

¹³ **ecdp** response to DLA reform consultation <http://www.ecdp.org.uk/home/2011/2/16/dla-reform-consultation-ecdp-response.html>

¹⁴ **ecdp** members share final views on PIP: <http://www.ecdp.org.uk/home/2011/8/31/ecdp-members-share-final-views-on-pip.html>

¹⁵ **ecdp** CEO gives evidence to the Welfare Reform Bill Committee <http://www.ecdp.org.uk/home/2011/3/30/ecdp-ceo-gives-evidence-to-the-welfare-reform-bill-committee.html>

¹⁶ **ecdp** report on Access to Work: <http://www.ecdp.org.uk/home/2011/3/23/our-access-to-work-survey-the-results.html>

to be the case both inside and outside of Essex and enabled ecdp to work towards preventing disabled people losing vital support currently provided through Access to Work.¹⁷

Disability Hate Crime

Aware that disability hate crime is an issue which affects many disabled people, ecdp set out to understand how our members experienced disability hate crime in their everyday lives.

Initially, research was carried out to give a picture of the national situation of disability hate crime and then a focus group and an in-depth online survey (49 responses) enabled people to inform ecdp about the situation in Essex. ecdp worked with the police, local councils and other disability organisations to understand the issues from their perspective. Eighteen months of work culminated in a major report on disability hate crime¹⁸, which lays the foundations for taking forward a practical model of work to address hate crime working with relevant partners across Essex.

We have also undertaken engagement and coproductive work on a range of other areas, including:

- Right to Control
- Social Care Green and White Papers
- Department of Health PA Framework Strategy
- Modernising Commissioning Green Paper
- Bespoke features for Community Care magazine and Guardian Society online.

¹⁷ ecdp report on Access to Work driver support: <http://www.ecdp.org.uk/home/2011/8/7/access-to-work-driver-support.html>

¹⁸ ecdp report on disability hate crime in Essex and beyond: <http://www.ecdp.org.uk/home/2011/5/25/disability-hate-crime-in-essex-and-beyond-a-report-by-ecdp.html>