Staying Healthy Topic – Feedback
How did people feed back on Health promises?

Visits by Michelle Stickland to LIG groups;
- 6th July 2015 Orange LIG
- 9th July 2015 Green LIG
- 14th July 2015 Blue LIG
- 22nd July 2015 Yellow LIG
- 20th August 2015 Extra Green LIG
- 4th September 2015 Purple LIG

- 8th September 2015 Feedback Session by Speakeasy Advocacy with Mildmay Oaks Patients (formerly Vista Hospital)
Orange LIG 06.07.15
Woodley Village Hall
<table>
<thead>
<tr>
<th>GP</th>
<th>Hospital</th>
<th>Health Passport</th>
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<tr>
<td>• Background preparation for people a month or so before an annual health check – (complex health needs)</td>
<td>• Learning Disability liaison nurses disappearing</td>
<td>• Incomplete Health Passports (providers)</td>
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<td>• Training Receptionists</td>
<td>• Hospital discharge South West team needs to work in partnership with the Community Learning Disability Teams</td>
<td>• Need to advertise more</td>
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<td>• Would like to be involved in meeting GP staff (Stephen/Debbie)</td>
<td>• There is evidence of good care and good patient experience</td>
<td>• OK if known to services</td>
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<td>• Make it simpler for us to understand</td>
<td>• More choice for food. Healthy food availability for relatives and visitors, not just burgers and chocolate etc.</td>
<td>• Hospital staff not losing them</td>
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<td>• GP’s to work with Dentists, Hospitals and care providers prior to admission</td>
<td>• Free hospital parking for everyone, some people would be on benefits</td>
<td>• Never heard of them</td>
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<td>• Raise awareness for people working with people with a learning disability</td>
<td>• Visiting my nan I found all the staff were smiling and happy, helpful despite being tired</td>
<td>• Do not have one, but I would like to have a look at one</td>
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| • Have to wait weeks or months for an appointment | • Experience of service users hospital stay  
  o Clinical care was excellent but people did not consider wellbeing for example, telling him where the TV lounge was  
  o Being in a single room  
  o Nurses were very nice at Princess Anne and they got the Dr out because I was so bad  
  o Patients were very nice and chatted to me  
  o Lack of knowledge by hospital clinical teams  
  o Details were given prior to a hospital appointment and day surgery, but when I arrived, no one at the hospital knew what was happening. Following operation no one told the carers where to take the service user | • Good for someone if feeling worried |
| • Receptionist asks what is wrong – too personal | | • Staff in hospital must read them |
| • GP Surgery will not let you make an appointment in advance and have to call back next day or after lunch (hard if busy or unsupported) | | • Someone to lead on completion of Passports, particularly in needs are complex and have many professionals involved |
| • GP staff not trained enough | | • Helps in choosing menu’s and in communication |
| • Too many long words | | • Seem to be variations – need a standard health passport |
| • Are chlamydia tests mandatory, as advised when signing up to a new GP this was a must | | |
## Green LIG – Service Users comments 09/07/15 meeting

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| - I like my GP.  
- My GP makes me feel better  
- Reception staff tell me what is happening  
- I have an Annual Check and they understand me  
- Pre-paid prescription card expired – I didn’t receive a reminder  
- Use electronic check-in  
- GP helps me fill form. Easy Read format  
- Support workers often have to phone GP as they are not sure about medication  
- Need to make sure that people understand them | - Who are Hospital Liaison  
- Reliance on family/carer to support patient in hospital  
- Hospital admission can prompt behaviour changes – patients placed in mixed groups  
- Lack of communication means that important information is not always handed over  
- I wasn’t sure about what I could or couldn’t do – therefore I wasn’t able to be independent  
- Food no good  
- Discharge Meetings – need better communication | - Health passports go the ambulance people and Hospital passports go to hospital staff who promptly lose them  
- Vital that hospital follow the health passports as when social care moves to health provision Adult Social Funding stops – No support or information  
- Great document but hospital don’t value it and just lose them – constantly having to be redone by providers  
- The hospital takes no view whatsoever from the parent/carer  
- Young person used health passport but there is no space for parents comments or personal details or management of behaviour, which is vital  
- Never had a health passport but would like one - how do we get one  
- Never been told by GP that these are available  
- Not sure if they have one but would like one |
## Blue LIG – Service Users comments 14/07/15 meeting

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| - More efficient Action Plans  
- Very good GP, always easy to get appointment on same day  
- Could be better if I could always see the same GP  
- Chaotic response in an emergency  
- Failure between GP and 111 service  
- GP doesn't make any reasonable adjustments and is not very helpful  
- Follow ups not good  
- My doctor is doing his job well  
- My daughter's doctor doing good job, but her care often don't know her well enough to support her well  
- People with Learning Disability often feel intimidated. I need support to make an appointment  
- Surgery not very flexible  
- Need consistency of support staff and knowledge of patient's health needs | - It is important for carers to know about people when going to routine appointments. The carer didn't know anything about my daughter (Basingstoke Hospital)  
- Even though I told staff my son was autistic, they made us wait 4-5 hours. The X Ray wasn't right so had to have another one. Why can't they get it right first time? Had to see 3 people prior to seeing a doctor (Frimley Park Hospital)  
- Wasn't treated with dignity – person using a walker was asked to wear a gown and bottom was exposed  
- Carer being allowed to be present during an X-Ray  
- When our daughter goes into hospital – we go with her  
- LD Liaison Nurses work with us when in hospital  
- Out Patients for Dentist very good (Basingstoke)  
- Appointments cancelled at the last minute  
- When you book over the phone, you don't get a letter to remind you  
- Need to be able to book more than 6 months in advance  
- Excellent Community team for people with LD  
- I felt safe. They told me what they were going to do  
- Didn't have a good experience  
- No discharge meeting as promised (Royal Hampshire County Hospital)  
- HDU/ICU too busy for people with LD  
- Thought needs to be given re support for people in hospital overnight. Hospitals do not understand “we cannot wait”  
- Parents are ignored | - 30 people answered Yes to having a health passport  
- It helps when I go to GP or Dentist  
- I don't need one  
- Used for my pre operation meeting, but when I went into hospital staff didn't know anything about it  
- Liaison nurses say they are very useful  
- Should be offered at Annual Health Checks  
- Community Teams are aware that people don't have these and are prioritising this  
- They are too complex  
- Sections are good, but danger is that people only seem to read the "Red" section  
- Heard about these in LIGs not from Health Services  
- Complex needs provider has their own health liaison person for in patients  
- Could be problem if emergency situation  
- GP's don't take them seriously |
Yellow LIG 22.07.15
New Forest Day Services
## New Forest Feedback

### Yellow LIG – Service Users comments 22/07/15 meeting

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<tr>
<td>• Dentist refused to see someone who had complex needs and wasn’t sure about Consent</td>
<td>• Planning for admission very good</td>
<td>• Can Health Passports be reviewed as part of the Annual Health Check?</td>
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<td>• I am able to see either a male or female doctor depending on my problem</td>
<td>• Doctors and nurses very good for Learning Disabilities</td>
<td>• Could they be scanned onto the HHR or RIO so if you have an emergency admission passports can be downloaded</td>
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<td>• My doctor tells me what is happening and asks for my consent for tests</td>
<td>• Food horrible – need more choice more healthy options</td>
<td>• Can the passport templates be put on the Hospital websites for download</td>
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<td>• I have to wait a long time in the waiting room – some people find this difficult</td>
<td>• Couldn’t sleep – too noisy</td>
<td>• I use my health passport, it helps to tell people about me</td>
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<td>• Offered early appointments, or longer appointments as long as advised beforehand</td>
<td>• No easy read info</td>
<td>• Nurse said “Too much info for people to take the time to read it all” (Carer)</td>
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<td>• Tells me on screen where I need to go in surgery</td>
<td>• Long wait for discharges</td>
<td>• Some people have hospital plans but are now moving to health passport</td>
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<td>• Will come out to do annual health check at home.</td>
<td>• Staff need to listen to carers more and write down what they say</td>
<td>• Hospital staff don’t know the passport has gone in with someone, or they sometimes go missing</td>
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<td>• Better planning for annual health check for people with complex needs – providers need to work earlier and GP’s to prepare. Sometimes I am rushed – need more time</td>
<td>• Help with medication needed – clarify with carer</td>
<td>• Not everyone is aware of passports</td>
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<td>• Depends on where you live. Good communication and local practices is important from carer/private?</td>
<td>• Staff are not aware of liaison nurses</td>
<td>• Good feedback from nurses on wards when passports have been used</td>
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<td>• Need some desensitisation trips to surgery (meet receptionists)</td>
<td>• Coordinated care not good</td>
<td>• Say it once is a good resource</td>
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<td>• Blood tests at home or surgery</td>
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<td>• Carers need to review passports</td>
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<td>• Same GP for people with learning disabilities</td>
<td></td>
<td>• Use easy read with people for medication to tell people what this if for</td>
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<td>• No easy read info</td>
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Extra Green LIG 20.08.15
Kingsley Centre, Bordon
Extra Green LIG for health – Service Users comments 20/08/15 meeting

**ARE YOU SUPPORTED TO BE HEALTHY?**

- Most people had a healthy breakfast – cereal, toast, fruit
- People said that they drank water, tea and milk
- Care Plans need to be followed up so that people know what is good and what is bad for you e.g. diabetes
- People need to be more engaged in why you shouldn’t buy certain drinks etc.
- Mum helps me with healthy eating
- I joined a Get Fit Programme. I go to keep fit class and I wear a pedometer
- People knew that smoking was bad for them. One person said that carers smoked near her and she could smell it in the car and on their cloths – she felt that she wasn’t able to say anything about it – felt she had to put up with it
- Carers do not know how to prepare healthy meals
- Staff should have training in healthy eating and home management
- Carers don’t have enough time so they prepare microwave meals
- They don’t know how to cook

**ENOUGH STAFF TO MAKE YOU FEEL SAFE AND TO ALLOW YOU TO DO ALL YOUR ACTIVITIES**

- There are not enough staff
- I am helped with activities and I feel safe
- I had a bad experience so mum supports me for important hospital appointments
- Hospital staff don’t ask me first if I want family or carers to go in with me to the appointment
- Parents have better knowledge of me
- Staff spent time with me in hospital when I was very young
- Staff take me out all the time
- I am supposed to get regular support hours but I sometimes have to phone up and ask where they are

**OTHER**

- Some people said that Basingstoke Hospital bad and some said good
- Southampton Hospital good
- GP bad
- One person said that when he was younger he used to do fun things – now he can’t because he is an adult – he is very sad about this
- In the last week someone went to QA hospital for a week – they were great, very person centred.
- Another person had the same recent experience of QA
- Need more info generally in terms of health
- Need ongoing support to explain healthy options – plan treats

**DO STAFF WHO SUPPORT YOU HAVE THE RIGHT KIND OF TRAINING**

- When I phone doctors, reception don’t always understand me, but I can understand them
- Hospital expects Carers/Family to look after people with complex needs. They don’t read paperwork and always ask the same questions again and again
- For people living at home with parents - who tells us about things
- Staff make appointments for me
- I have a monitor so if I fall, someone will help me
- Hospital don’t communicate – they never listen to what mum or carer says
- I can’t read – mum and dad help me pay bills
- Doctors in hospitals don’t understand complex communication needs
- I am not always seen by my own GP so communication is difficult – not all GP’s know how to communicate
- I had a bad experience with a social worker that I was placed with – I wasn’t supported to make decisions – not on my side
- I can choose my own activities when at Kingsley Centre – I am being supported to save so that I can go on holiday
- I know what is in my support plan – but other people don’t always fully understand
- People need to be more engaged with plan – don’t just tell us that we can’t have something
- Extra Green LIG for health – Service Users comments 20/08/15 meeting
Purple LIG (Go-LD) 04.09.15
Winchester Discovery Centre
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| - Not good to see a different Doctor. If you see a different GP you have to repeat things  
- Sometimes you have to wait a long time to go in but they tell you that there is a delay and the doctor says Sorry for being late  
- I am asked if it is ok for a student to be present  
- My doctor is helpful. I can ask my doctor to tell me again if I do not understand, but it would be good to have details written down so that I can take it away with me  
- I would like to be able to ask questions after my appointment as I do not always think of any at the time  
- Since moving to Winchester, I have had 2 very nice doctors at St Paul's Surgery. They are now retired and I being registered with a new doctor at the surgery who understands people with a Learning Disability  
- I am with St Clements and have never been offered an Annual Health Check  
- I go to St Pauls and I had a smear test and I did not like it, it was very uncomfortable  
- I am offered a double appointment and doctor will ask me if I want it written down to show my family  
- I need more information so I can understand  
- GP was slow to make referral for exercise scheme and people lose enthusiasm whilst waiting and may give up  
- My dentist used to send me a text message to remind me when I had an appointment but they stopped so I missed my appointment and they took me off the list | - Nurses were nice  
- Hospital was clean  
- I could understand the signs around the hospital  
- Reception cannot always understand people with a Learning Disability so we need a support worker with us  
- I have to wait too long for appointment  
- Directions can sometimes be confusing  
- They were kind when taking blood, they were very nice  
- Nurses did not look after me  
- I would like my support worker to stay with me at the hospital | - 11 people said that they had a hospital passport.  
- 4 said that they did not have a health passport.  
- 1 person said that they did not think they needed a health passport  
- Passports are helpful because of the traffic lights |
In-patient Feedback by Speakeasy Advocacy at Mildmay Oaks Hospital, Winchfield 08.09.15

Patients were asked about 3 areas of their care and treatment;

- Restraint
- Care & Treatment Plans
- Support to finish treatment and leave hospital when ready
## Mildmay Oaks Patient Feedback

<table>
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<th>Restraint;</th>
<th>Care and Treatment Plans;</th>
<th>Support to finish treatment and leave hospital when ready;</th>
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</table>
| • Report of face down restraint being used a couple of months ago | • Care plans are kept in the office and available for people to read when they want  
• Plans are written in a way that people can understand and they can have a copy  
• Staff write care plans without them but then go through them with the person. If people are not happy with something on their plan they can tell staff and this will be changed  
• Patients are allowed to attend ward rounds  
• Patients knew about their care plans and had input into them  
• One patient knew what medication they were on but did not known why they had to take it or what it was for  
• Have several ways to complain if not happy  
• They liked the staff and enjoyed having staff from different countries because they told them interesting things about where they lived.  
• Felt that sometimes the staff were unhappy especially when the shift change was late and “it means we don’t get out supper until late”  
• Can ask for fruit from the kitchen whenever they liked  
• GP visits the hospital twice a week  
• “The staff talked to my doctor here and that helped them understand me” | • Pathway meetings are every 3 weeks and helps them to have a goal to work towards (discharge).  
• Know what they have to do to reach their goals  
• Did not know how long it will take to reach goals  
• Hospital is helping them develop skills for when they leave and have group sessions with an occupational therapist  
• Enjoy the work they do with Tracey (Patient Engagement) especially the videos about people with a learning disability sharing housing in the community. This made one person think about what it would be like to live in a house with other people  
• Social workers and health professionals working with them to leave hospital “My social worker is helping me move” |
What People Said Was Good

GPs:

• Very good easy to get appointment on same day
• My doctor is doing his job well
• I am asked if it is ok for a student to be present
• I have had 2 very nice doctors at St Paul’s surgery who have now retired and being registered with a new doctor who understands people with a learning disability
• I am offered a double appointment and doctor will ask me if I want it written down to show to my family
• I can see either a male or female doctor depending on my problem
• Offered earlier appointments
• Blood tests at home or surgery
• I like my GP
• My GP makes me feel better
• I have an annual health check and they understand me
• Use electronic check-in
What People Said Was Good

Hospitals;
• Carer allowed to be present during an X-ray
• When our daughter goes into hospital we go with her
• LD Liaison Nurses work with us when in hospital
• Out patients for dentist very good (Basingstoke)
• There is evidence of good care and good patient experience
• Visiting my nan, I found all the staff were smiling and happy, helpful despite being tired
• Nurses were very nice at Princess Anne and they got Dr out because I was so bad
• Patients were very nice and chatted to me
• Nurses were nice
• Hospital was clean
• I felt safe they told me what they were going to do
• I could understand the signs around the hospital
• They were kind when taking blood, they were very nice
• Planning for admission very good
• Doctors and Nurses very good for Learning Disabilities
What People Said Was Good

**Health Passports;**

- It helps when I go to GP or Dentist
- Should be offered at annual health checks
- Community Teams are aware that people don’t have these and are prioritising this
- Good for someone if feeling worried
- Helps in choosing menu and in communication
- Passports are helpful because of the traffic lights
- Some people said they had a health passport
- I use my health passport it helps to tell people about me
- Good feedback from nurses on wards when passports have been used
What People Said Was Good

Other Feedback;

• Excellent Community Team for people with a learning disability
• Say it once is a good resource
• People are supported to have a healthy breakfast e.g. cereal, toast, fruit
• I joined a ‘Get Fit’ programme. I go to keep fit class and I wear a pedometer
What People Said Was Not Good

GPs:
• Could be better if I could see the same GP
• Chaotic response in an emergency
• Failure between GP and 111 service
• GP doesn’t always make reasonable adjustments
• Follow ups not good
• Surgery not very flexible
• Need consistency of staff
• Training of Receptionists – they ask what is wrong – too personal
• Have to wait weeks or months for an appointment
• GP staff not trained enough
• Too many long words
• I need more information so I can understand
• No easy read information
• Support workers often have to phone GP as they are not sure about medication
What People Said Was Not Good

Hospitals:
- Made to wait 4-5 hours
- Wasn’t treated with dignity – person using a walker was asked to wear a gown and bottom was exposed
- Appointments cancelled at the last minute
- When you book over the phone you don’t get a letter to remind you
- Need to be able to book more than 6 months in advance
- Didn’t have a good experience
- Parents ignored
- No discharge meeting as promised (Royal Hampshire County Hospital)
- HDU/ICU too busy for people with a learning disability
- Learning disability liaison nurses disappearing
- Suggest free hospital parking for everyone, some people would be on benefits
- Lack of knowledge by hospital clinical teams
- Nurses did not look after me
- Directions can sometimes be confusing
- Couldn’t sleep too noisy
- Food horrible need more choice more healthy options
- Long wait for discharges
What People Said Was Not Good

**Health Passports:**
- Used for pre-operation meeting but when I went into hospital staff didn’t know anything about it
- They are too complex
- Sections are good but danger is that people only read the ‘RED’ section
- GPs don’t take them seriously
- Incomplete health passports (providers)
- Need to advertise more
- Never heard of them
- Staff in hospital must read them
- Nurse said “too much info for people to take the time to read it all” (carer)
- Not everyone is aware of passports
- Health passports go to the ambulance and hospital passports go to hospital staff who promptly lose them
Other Feedback:

- Co-ordinated care not good
- Can there be free parking for everyone, some people would be on benefits
- Staff don’t know how to cook
- Carers don’t have enough time so they prepare microwave meals
- There are not enough staff
- I am supposed to get regular support hours but I sometimes have to phone up and ask where they are
- One person said that their carers smoked near her and in their own cars which they use to take people to services
Which three key themes would the Partnership Board /LIGs like to be prioritised for Action?