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West Suffolk
Clinical Commissioning Group

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Date: 14 May 2013

Dear Colleague

'Patient Revolution' event feedback

Thank you for joining our 'Patient Revolution' event on 1 May. The purpose of this letter is to share with you a copy of the notes taken on the day. The notes have been copied word for word, so do excuse any lapses in grammar!

The CCG governing body will receive a report of the event at its meeting in public on 5 June. We will then consider how we incorporate your rich feedback into our commissioning going forward. During the coming months we will communicate progress updates chiefly via our newsletters. At the next 'Patient Revolution' event – 2014 date to be confirmed – we will report back with examples of how we have listened and responded to your input.

Many thanks for your continued support.

Yours sincerely

Dr Ed Garratt
Chief Operating Officer

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Patient Revolution 1 May 2013

Open Space Questions

1. How can emotional needs inform a patient centred approach?
2. Needs of black & ethnic minorities (BME) in West Suffolk
3. Can creative activities (music, singing, painting, etc) reduce isolation and improve health conditions for the older person?[2]
4. When will social care services funding by Suffolk County Council (SCC) be merged into NHS provision?
5. Patient participation at GP Practices
6. Is stroke support in the community working?
7. What can be done to improve hospital transport, particularly over long distances?
8. Educate on benefits of complementary therapies, yoga, pilates, medications, etc and offer alternative treatments to drugs and surgery
9. How can we support and encourage dementia enabled village?
10. Learning disability physiotherapy – who provides this?
11. Why can GPs not have access to patient data kept by hospitals and vice versa?
12. How can we work more closely with the doctors and support teams of our local practices
13. How do we manage people who over use emergency services?
14. How can we better promote the positive role of care homes in our community?
15. How do we stop patients feeling isolated after sight loss diagnosis?
16. Could the CCG consider providing financial support to voluntary organisations?
17. Supporting those with chronic long term conditions – how do we maintain quality care and support?
18. Family/volunteer carers need support. How can we look after their needs?
19. Not everyone likes or responds to medication. How can complementary therapy help the CCG meet their priorities?
20. How can we be sure that what happened in Mid Staffs isn't happening here?

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21. There are at least 2000 people with learning disabilities in Suffolk and only 3 hospital learning disability liaison nurses in Suffolk
22. How can we establish a person's needs in a time of crisis?
23. Neurorehab
24. Why won't hospitals employ eye clinic liaison officers (ECLOs) as part of their staff at point of diagnosis?
25. How to prevent mental health problems in children by working in schools
26. Governance – why are private supplies of healthcare, e.g. Serco, not complying with statutory law – Freedom of Information Act?
27. Joined up commissioning for neurology
28. What is the CCG relationship with the clinical support units (CSUs)?
29. What support can be provided for people who don't qualify to enter secondary mental health services? But one suffering mental health difficulties, which make day to day life hard and they need support?
30. What links are being made between children & young people (CYP), Suffolk County Council (SCC) and the CCG to analyse CAF/TAC data to identify children & young people and family needs?
31. How can we ensure people without access to computers are consulted and informed?
32. Could we return the out of hours service back to the doctors instead of the service formed out to completely disassociated body the young and old need a familiar face?
33. How do we promote awareness to this health care service to better support and look after their support needs (learning disabilities)?
34. Carers for patients with mental health problems; how do we support them?
35. Out of Hours
36. Engagement with the voluntary sector
37. How can we integrate substance misuse services to ensure appropriate use of services?
38. Accident & Emergency at West Suffolk Hospital
39. Hospital Transport
40. West Suffolk Hospital Challenges
41. General discussion about health services

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How can emotional needs inform a patient centred approach?

- Family carers
- What about emotional needs of carers?
- Often highly emotional
- Question should be: How can emotional needs information a patient centred approach?
- Carers often not on the back-burner – overlooked
- Need emotional training
- Family support groups can assist with emotional needs – can be much more effective than medication e.g. anti-depressants
- Difficult because patients and carers often don't know they support they need emotionally
- 60% of carers – Alzheimer's
- A lot of hidden emotional needs – don't have a culture yet where people can openly talk
- Emotional needs audit (EMA project) – gets people to focus on whether they have the support they need, anxiety, etc.
- How well your need are being met and what could be done differently
- Whether people feel they are being stretched, or not challenged enough
- A clinical approach to emotional needs is not intuitive- it's clinical by nature and misses the mark
- Human empathy can often be overwhelmed by clinicians
- Vast NHS structure can often obscure human aspect of care – time and target driven
- A clinical approach can actually cost the NHS much more
- E.g. clinical took pulse, suggested head anxiety - led to ECG (echo cardio gram) and other tests. If they had just talked to me, they'd know I was completely fine
- Don't rely too much on systems and process –talk to patients!
- Ensure that users of mental health services are not excluded from substance misuse services and vice versa
- Integrate mental health and substance misuse services
- Not turning away from people because they present with mental health issues sporadically or regularly.

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Needs of black & ethnic minorities (BME) in West Suffolk

- 7000-8000 BME across West Suffolk
- Suffolk Refugee Support (Ian Stewart) - see big issues with communication e.g. visiting GPs, health specific problems e.g. Asian population and diabetes.
- Amongst the refugee community there is currently a baby boom
- Learning about living on England, prenatal and post natal care
- Working together with health visitors in Ipswich on dedicated groups for these families
- In Ipswich there was dedicated winter funding projects- the funds were used for health education for women- especially contraception as many women didn't want any more children.
- Refugee groups- often MH problems, especially schizophrenia, due to what they have experienced previously. Often not registered with GPs. Lots of post-traumatic stress disorder issues.
- Children are often affected with language issues as English isn't their first language.
- Rep from WSFT- they're having issues getting feedback from EM patients using WSH services.
- BME Healthwatch is mean to be county wide, but mainly focused in the East and looking to link in with the West.
- Also works with 'Embedding Ambassadors in Community Health (EACH)
- Supports patients (4-5) in West Suffolk. Works with West Suffolk Hospital and social services. They have criteria that patients must be over 50 years old.
- Chair= David Evans
- Patient Engagement Group at West Suffolk Hospital- can they get a representative from EACH to attend? Jo Finn was supportive of this proposal.
- Bangladeshi Support Centre- a voluntary organisation supporting BME communities (approx. 45 nationalities)

- 100's of 'Indian' restaurants housing Bangladeshi families. In Newmarket the BME population is more than 10%.
- Very keen to link in with health care in West Suffolk. They currently travel regularly to the West. Keen to link up communities and to focus on prevention rather than just picking up the pieces.
- e.g. Eastern Spice restaurant tin Ipswich has created a parallel 'health eating' menu. The Anglo- Chinese community also promoting the same healthy eating idea.
- Marginalised and Vulnerable Adults (MVA)- meeting with Tracy Sadler tomorrow to review the service delivery of MVA, which is contracted with North Essex.

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Can creative activities (music, singing, painting, etc) reduce isolation and improve health conditions for the older person?

- Trying everything making dementia sufferer happy
- Age UK forums on dementia
- Difficulty of finding evidence base when individuals need alternative therapy
- Where do anecdotes become evidence?
- Assessments need to be individual – how can statutory and voluntary sector meet the need for an individual – maybe have a social support worker.
- Can we have equivalent of children's play worker?
- Assessment of what makes person happy reduces burden on carer and patient by identifying activities which makes them happy – risk of carer burnout.
- Need to reduce social isolation
- Can we revise the expert patient programme?
- How to promote self-awareness
- Useful to be aware of your body

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When will social care services funding by Suffolk County Council (SCC) be merged into NHS provision?

- This has been discussed many times over many years but not very clear progress to date
- Lady with social services background feels there should be one pot of money available broadly to cover both areas of health and social care. Often frustrating for patient not knowing how to access services
- Lady with local authority background – now works in similar areas previously undertaken by social workers but not much more broadly
- Essex is piloting a scheme to understand what support is needed – first action is to identify how the whole pot of public money is spent and to then identify how budgets can be distributed. Example of Waveney CCG and Social Services working together
- Lady with carer/elderly care background spoke of difficulty to locate District Matron. Often problem of knowing who to contact when private companies are involved
- Where is Serco in this? Often responsibilities are passed back to patient, e.g. incontinence pads are passed back because they are no longer funded as they had been before.
- An excellent example – a patient is working on a MS Pathway pilot scheme initially in Norfolk involving 20 patients (out of 8,000 patients with neurological conditions). Already in discussion with WSCCG but hoping it will be a domino effect. Early intervention important – looking an enablement, education and ability to navigate system. Looking at money following patient regarding their care.
- Key is picking areas where health and social issues come together and patient involvement is very important in the process.
- Key is communications and joint decisions need to be made. Forums for discussion are Health & Wellbeing Board and Suffolk Commissioners Group. This is happening at senior level but needs to be cascaded down.
- Are there any social services present? It was known they were invited but needs to be involved in discussions.
- There are cost benefits to both organisations partly because it does away with administrative duplication.

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Patient Participation at GP practices

- Can CCG exercise some guidance as to how patient groups at GP practices are run? Can the CCG offer advice? In terms of practice, etc
- Good information from GP practices must be collated and centralise for the benefit of patients
- Lack of information re: membership of GP patient groups given to patients at practices
- Join the Health Forum to get involved
- Groups only meeting in a “virtual” way and not face to face which does not promote user involvement and aren’t effective
- The CCG needs to put together guidance for GP practices which is monitored and followed up on the running of PPGs
- How do you attract people to group? Hired to get people from villages to surgery areas and targeted them
- If doctors are on board they could identify patients to be involved
- Try to get representation from all the villages on the patient forums
- How do you make it effective?
- Can you use Parish Council networks and village newsletters, church newsletters etc?
- “Buy in” from GPs is sporadic. More needs to be done to ensure GPs take it seriously
- Use of patient surveys to get ideas from patients – making them meaningful – clear/open communication
- Produce Terms of Reference to give focus to group
- Could the GPs be more active in approaching to participate?
- Important to have regular meetings, once per month, everyone 2 months – too long between meetings
- Need to regularise times between meetings to keep continuity of group and issues

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- Nahaal Associate are patient groups – website with advice
- PPG website has several constituency, etc
- Survey on particular issues
- Market Cross in Mildenhall hold open events for groups/patients. Can be subject based, e.g. diabetes
- Newsletters – virtual and paper effective
- Advice on Terms of Reference/constitution etc. Regulated for patient groups
- Debate whether GPs should/shouldn't be present at patient forum meetings
- Potentially should be there for part of the meeting and then leave
- Patient participation posters up in GP surgery waiting rooms

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Is stroke support in the community working?

- **Recent research**
- Past stroke support
- Family carers
- **Community services**
- Buddying up service
- Mentoring by familiar people
- Information that is accessible
- Phone
- Prompting
- Positive entrances do not hide behind ‘confidentiality’
- Support volunteers
- Social/emotional/relationship support
- Partnerships – Stroke Association/Headway/Hospital/SCH, etc
- Joint commissioning of solutions
- Clinicians need to be better informed
- Link with Care Co-ordination Centre
- Goal centred planning – patient contract
- Link pathway with whole support systems – voluntary organisations, slow stream rehab
- Waiting list gap from acute to community
- Discharge planning is key!
- Acute treatment – best hyper acute, most competent, timely, with excellent community support
- Other specialist services have a centralised approach
- Do we want telemedicine as the answer?
- Patient view – want expert 24/7 service
- Lack of capacity in therapy – how does the skill and knowledge spread?
- Weekend cover requires 7/7 services
- Long term relationship required
- You want someone to talk to!
- Network the support – recreated

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What can be done to improve hospital transport, particularly over long distances?

- Impact on patient from external service changes - are my needs being met?
- Access to services when several different local/broader services available and when it's changing
- Spinal unit for Suffolk in Sheffield
- Grater needs as condition changes and aged
- Last 30 years spinal services are improving and people are living longer
- Where do I go when services are contracting, professionals are retiring?
- CCG advertise services more and identify people in practices who need support
- Can't phone up hospital so patient forced to travel for pressure ulcer. Information that could have been obtained more easily – lack of local level knowledge
- Assumed knowledge of services within the system and its assumed patient should be the expert
- More information at practice level
- GPs should be prepared to contact specialists on behalf of patient
- Specialist does not encourage you to go straight to them but GP doesn't have information needed
- Use patient practice engagement groups to channel information back
- Support for self-management
- How do we define long term conditions?
- Increased longevity of people with LTCs (long term conditions)
- Perception of good cancer support groups
- Confusion around changes and whether they were CCG initiatives
- Patient just wants to get on and manage
- Community has to share information more if they let their needs known, there is a perception the CCG will meet these
- The change when a service is moved – community get used to a service and then they move – why aren't the community consulted?

And then can we consider the impact of this when going out to procurement?

- Confidence in GPs
- Localised support at practices
- Dependant on GPs to guide back – patients need to re-challenge GPs
- 5 day surgery (practice) – patients no not get sick at those set times
- Understanding of aging population
- Higher expectations of patients because of increased life expectancy " I don't want to be vegetated", "I want good quality care"

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Educate on benefits of complementary therapies, yoga, pilates, medications, etc and offer alternative treatments to drugs and surgery

- Yoga may help co-ordination in Parkinson's disease – help with balance.
- Weight bearing exercises to strengthen bones to help with osteoporosis
- Evidence-lead approach accepted. Use local population to do some trials re: success of treatments
- Anecdotal improvements following complimentary therapies
- Doctors should give me more than just drugs advice on what else I can do for myself
- Prescription pad to be used by doctor to recommend other therapies to try
- Pain clinic offers acupuncture locally.
- Deal with causes of pain rather than just prescribing pain killers e.g. relaxation tendencies
- Is it right to ask patients to spend money on treatments not proven to work?
- Concern about addiction to pain killers
- Give patients choice between medications and alternatives
- Support patients with learning disabilities to access alternative therapies. Funding issues to be addressed
- Doctors can refer to exercise classes. No need for patients to fill in forms from county council
- No one assessing e.g. improvement in balance following e.g. pilates or yoga
- Mental health improvement linked to exercise well known
- Apply for funding, to Suffolk Foundation, to do some research into benefits of compliment therapy.
- Shared decision making is important. Patients often keen to delay surgery as much as possible, exploring all options before surgery.
- Offer taster day for patients to get idea of possible benefits of alternative therapies. Need to know what realistic options are.
- More towards self-care. Person centred. More information for the public
- Things may change again in 2015, so move quickly now to make changes
- 1 in 9 people in states doing yoga
- Keen for trials to be done in Suffolk on yoga, pilates, etc

- Acupuncture has helped some patients
- Deliver prevention to save money. Include in public health (PH) agenda.
- Empower people
- Everything should be linked so all know what services exist
- Manchester PCT has centre for complimentary therapy. Remodel that here in Suffolk
- Dance on prescription part of patient choice
- NICE stresses medication second after other options explored, e.g. counselling
- Do people have enough awareness of their emotional needs?
- GPS has database for accessing patients with long term conditions that could be targeted by those offering alternative therapies.
- GPs are gatekeepers preventing access to which patients would benefit
- Doctors dispensing should not make money from prescribing medications
- Clinical nutrition only an optional module for GPs to study
- GPs only see patients at start of their problem so don't have access to patients for prevention of illness.

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How can we support and encourage dementia enabled villages?

- Focus on places with local hubs, i.e. shops
- Telemedicine calls
- Use families
- Use parish councils
- Community based networks of support
- Needs to be support and work with care homes equally to ensure provision for dementia patients
- Difficulty for patients in hospital care needed to ensure they are safe to go back home
- Correct care packages needed in the community to enable them to stay in their own home
- Not enough support available to ensure respite so that carers don't end up in hospital
- Educating public – good neighbours enabling people to signpost for support
- Dementia friends
- Use parish council – community café, churches together, good neighbour scheme – active things forward.
- Training for family/carers to enable them to support person with dementia

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Learning disability physiotherapy – who provides this?

- For new referrals is it going to be a focused piece of work or a long term support?
- Will learning disability physio needs be picked up by mainstream?
- Is it really a worry if you don't have the continuity of professional knowledge of patient's communication problems?
- Will there be enough time given for physio to be flexible and be able to explain treatments to care staff on different shift?
- Worries about lack of continuity – will there be a different physio each time who will not have the time to get to know the patient?
- Who will have the knowledge about all the specialist equipment needed?
- Who will provide this service after the summer as NSFT (Suffolk) will not have community physio posts?
- Will new referrals still be accepted?
- Who will take on the care plans that are already in place?
- Concerns about potential communication problems, independent clients with learning disabilities may not give complete information and mainstream physio's are not appropriately trained to understand people with learning disabilities to ask the right questions to get the necessary information.
- Should mainstream physio's have additional training to deal with this type of client?
- Specialist at the moment liaise with social services, put into place detailed care plans and ensure that all the physiotherapy needs of the patient are dealt with.
- Who will do this in the future?
- Will mainstream physio's be trained up to do this role and will they have time to provide the same level of specialist care?
- Currently lead professionals co-coordinate the care of the patient and the
- Specialist trained learning disability physiotherapists are part of the team, they don't just come in provide therapy for the particular problem they are there for and go until the next session.
- There is a concern that severely disabled people will lose out on care as mainstream physio's are not specialized in the type of care needed.

- Could there be a consultant learning disability physiotherapist that could be a point of contact to offer support to mainstream physio's in complex cases?
- They could share knowledge and advice on managing the situations with the best outcome for the patient.
- Could there be an overlap period where existing specialist learning disability physiotherapists work with mainstream physiotherapists to do some intensive training to aid the transition?

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Why can GPs not have access to patient data kept by hospitals and vice versa?

- Hospitals and doctors – why can't they share patient information? Specifically medical history/drugs prescribed?
- Tests taken and not followed through feedback, i.e. if diagnosis ok, not explained
- Not also clearly explained to patient: needs further explanation/translation of what test results show. Got very good explanation from visiting local pharmacy
- Patient has the right to the appointments/consultations to follow through
- Should not have to feel grateful for the GPs time
- Haverhill had best health centre – shut down and money spent elsewhere in Suffolk. Haverhill treated like a village. Prefer walk-in appointments. New centre have to say and wait no matter how long it takes. You cannot pop in and pop out
- Dr Selby – his surgery – tried desperately to see Dr Selby and was not allowed, always sees a locum, thought it was patient choice?
- GP practices/hospitals/community healthcare to share data. Is trying to get this happening.
- Difficult to share data without prior written consent, the cost of writing to patients is extremely high
- **Other options**
- When patient is in the surgery collect the permission
- Public awareness campaign – telling patients unless they say otherwise, you records will be shared.
- Patients get choice from GP of where they would like to be referred on to, i.e. WSH/Addenbrookes
- Only county in England that does not do summary care records – shared data, i.e. if somebody enters A & E and is asked whether record can be accessed – SoH(?) cannot access this.
- The difference between 2 hospitals – cannot share data as they have different IT systems even down to blood test results sharing.
- Patients – use your voices. Encouraged to write to the practice; encouraged to write to the CCG.
- Join the practice patient participant group

- Shared patient information to flow around consultants who are response for patients help.
- Patients want access to their own records

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How can we work more closely with the doctors and support teams of our local practices

- Question: How well trained are the practice managers?
- Answer: patient put through to someone not on that day – leave voicemail
- What is the point of being put through when the person isn't there? Why not put through to someone else
- For it to work it needs on wall – do you think you could work with us – volunteers?
- Bring down wall between staff and patients
- Everyone has something to offer
- Practice need to support demands
- Suggestion: Doctors limited in provided tip-top service – use the voluntary talent of others! (I.e. legal fund) (Local angels)
- GPs need regular MOT- skills review
- Encourage with useful suggestions what works locally
- People should be made aware of what medical services cost – encourage people not to waste their time
- GPs need to be tough with patients – do what is in patients best interests not bow to patient demand if unavailable/not beneficial
- Promoting self-management of health, i.e. health diet in obese patients
- Patient involved in their care
- Appreciate GP/NHS service
- CCG to keep people informed of services/facilities in pipeline

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How do we manage people who over use emergency services?

- Example of problem: 90year old patient with shortness of breath who has an 'emergency button' that can be pressed to contact the emergency services. The ambulance crew visited the patient that night and notices it was the same patient they had visited the previous morning. There was nothing wrong with the patient so they were left at home. The patient has called the ambulance service 5 times in the last month and there is never a need to admit the patient to hospital as there is nothing wrong. The patient has 4 carer visits per day. This patient is wasting vital ambulance service resource and taking it away from patients who have life threatening conditions. How can we stop the patient from doing this?
- The services are there but they're not well co-ordinated
- Need more integration with community services to keep patients safe and happy at home.
- The patient is pressing the emergency button because they are lonely. They are comfortable and have their own medicines but call 999 for company. They are wasting money and resource by doing this.
- The patient will get 4 x1/2 hour carer time per day which isn't enough. The patient needs more integrated care and needs to know the services available to them.
- We need a risk stratification tool to identify these patients and how they can be supported.
- Better planning and sharing the vision.
- Involve the voluntary sector and families/friends/carers
- Take ownership – the CCG should drive this.
- Is A&E attuned to the services available to the patients? A&E consultants aren't aware of all the patients need and they need to think more holistically and involved other groups in A&E (e.g. involved Age UK in A&E).
- Need to do more work in GP practices as it's not just about medicine. GPs need to look at social circumstances and ensure patients are aware of all the other services available to patients to direct them to these accordingly. The patients don't know the services available to them.
- Paramedics are completing repeated paperwork for call-outs to these types of patients.
- The system is failing the patient.

- Paramedics request the ‘case assessments’ by the GPs for patients making repeated calls to 999 as patients need to be educated when not to call out the ambulance.
- 70% of 999 calls are not for life-threatening emergencies
- Paramedics are more involved in domestic and social issues and patients who can’t access the correct services therefore they just call 999 and are using up vital ambulance resource.
- Need support from mental health teams and GPs and social services
- Some patients call 999 if they’ve run out of medication because they don’t know what else to do
- The 111 services doesn’t always give patients the correct advice, sometimes they refer patients to hospital if they’ve run out of their medicines.
- There is a culture of most services saying ‘our department closes at 5pm’ and then the ambulance service can deal with all the problems outside of this time
- Some patients who call their GP surgery and are told it will be 6hour before the GP can visit the patient because it’s not an urgent issues means the patient will go to A&E to be seen.
- 111 is causing more work for the ambulance service than helping. The default position is for 11 advisors to call the ambulance service. There have been incidences where a patient says to a 111 ‘I do not need an ambulance’, but the 111 advisor has already requested for an ambulance to be sent to the patient.
- 111 is a good idea and fully supported but it needs to be filtered better and not all directed to the ambulance service
- For the patient who keeps making unnecessary 999 calls, this needs to be stopped. It shouldn’t take the patient making 10 repeated 999 calls before the problem is dealt with. We should have responded to the patients’ needs after the first couple of 999 calls to identify why the patients is making unnecessary calls to 999, rather than allowing him to continually make these calls. Age UK should not visit the patient. Carer four times per day for 30 minutes is not enough – it’s about the quality of social care given to the patient. The ambulance service is being used inappropriately by the patient because the patient doesn’t know the correct services available to him. The patient needs regular assessment. The ambulance form that is sent to the GP needs to be acted on. We need a plan for the patients care. Should mental health services be involved?

- The patients' needs are not being addressed if they are frequently using the emergency services. These type of patients need to be identified and have all the necessary resources available to them to support the patient.
- There is miscommunication between various specialists and GPs and community services. Proactive management of patients is required to work out a treatment plan for these complex patients and to ensure GPs and specialists work together and that all essential services are induced in the treatment plan. If a patients needs are properly met then they won't call 999 when it's unnecessary to do so.
- Patient's misusing the ambulance service need to be flagged and the system for their care reviewed and actioned. The patients' medical and social needs should be reviewed. All the possible voluntary and community services need to be made available to the patient.
- There needs to be a 'net' – community services can't work in isolation.
- Patients with complex care issues need to be proactively identified and managed and involve the patient in their care and liaison with services.
- The services themselves often just pass on responsibility to other services without resolving the problem. They need to identify who is best to help the patient. The problem can't be fixed by telling the patient not to call 999.
- Linking health and social care is vital.
- How can we ensure the money goes to the right service? One area will take a budget out to fund another area.
- We need to make more use of the voluntary sector.
- Patients are discharged too quickly from hospital without the right services in place. This means the patient will call 999 when they get home as they don't know what else to do.
- NHS staffs don't know enough about the 111 service. Feedback about the 111 service is vital. 111 staff also need to recognise when resource is lacking.
- We have finite resources that need to be used wisely.
- We need to consider the whole patient picture and not deal with issues in in isolation.
- The CCG needs to have info on all the services available and stress test them.
- We 'run to meet the average demand' – 999 is an essential emergency demand, we need to manage the peak demand.
- Need to integrate all services

- Another example was a mental health patient who called 999 and was going to commit suicide. The patient had a mental health team leader but no one could get hold of the team leader on a Saturday night. The paramedics therefore had to stay with the patient and the only option was to admit the patient to hospital. mental health services need to be accessible to patients 24 hours per day.

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How can we better promote the positive role of care homes in our community?

- Suggests an open day to promote social/ friendship where there is support too.
- Support celebration of care home diversity e.g. different things they do
- Going Extra Mile awards are good
- Additional Info: Care homes are ignored and isolated. If you do not look for information as a care home you don't get it.
- Barbara mentioned training programme and a massive push with medications.
- Big push to keep people in their own homes but for some that does not work.
- Choice should be promoted but need funding to support
- Difficulties with funding so how can WS CCG be imaginative about it?
- Suffolk Association of Independent Care Providers (SAICP) - Action- Barbara to meet SAICP to see how we can work together.
- District Council- asked care homes what care homes would want. Suggestion of using care homes as venues .g. Livewell sessions.
- Day services
- Supported living
- Entertainment for people
- Appreciative enquiry- might mean resources can be taken further.
- CCG/ social services must have a more positive view of care homes/ nursing.

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How do we stop patients feeling isolated after sight loss diagnosis?

- To have an Eye Clinic Liaison Officer present at all hospitals to provide advice and guidance, options and support choices.
- An Eye Clinic Liaison Officer would provide patients with face to face understanding. They give their contracts numbers to give reassurance to the patient that they do not have to make instant decisions.
- Need an appropriate befriending contact number to be made available.
- Emotional support for early intervention at point of diagnosis
- Transport for V1 people who have no means to get to hospital.
- Access into hospitals to the eye clinic. A lot of eye clinics are at the back of the hospital – let's have them all to the front.

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Could the CCG consider providing financial support to voluntary organisations?

- No funding available for primary care clients who want to attend services run by charities/voluntary sector
- Voluntary sector/charity save money in the long run
- Reduce need for secondary care
- Prevention
- Secondary care criteria is more strict, meaning more people managed by GPs – they still need access to services
- Work of voluntary groups/peer support/charities/carers need to be recognised financially by CCGs
- CCGs need to listen to voluntary sector experience in identifying gaps
- CCG input into SCC tenders that voluntary sector have to apply for
- Could the CCG have a person whose role it is to link with voluntary sector and learn what we do?
- Providers of services should have opportunities to present to CCG/GPs
- Providers don't necessarily have the skills, expertise and time to show we are clinically and financially viable
- Can CCG set up pilot projects to support different services with voluntary sector to demonstrate value?
- Examples:

Better Health Outcomes Housing Employment Social } Maslow's hierarchy of needs

- Gap for services is widening, as people need to get so unwell to access funding or services
- If CCG could empower GPs to access the services that people need, when they need it
- Could there be a provider event/market place for voluntary sector to make themselves known to CCGs? Then form a directory?

integrated working

- Huge focus on patient engagement – what about provider engagement?
- Haver a membership advisor – can there be a “third sector or provider officer”?
- When they do fund and it stops, the provision stops
- For funding needs to be well managed, strategic, outcome focused and holistic
- How can CCGs provide security (financially) for ongoing projects in the community?
- The voluntary sector is full of professional and experienced staff who can’t be secure in their jobs as constantly fighting for funding
- Voluntary sector also supports carers and provides respite for families
- Where are these neighbourhood teams – I haven’t been consulted and I have written to every GP in Suffolk?!
- Has the CCG adequately consulted with SCC and NSFT (Norfolk & Suffolk Foundation Trust) about current service provision?
- Prevention is better than cure – the voluntary organisations do that
- The CCGS need a presence in meetings/groups, e.g. VASP, health & wellbeing, in order to see the good work that goes on
- Voluntary organisations save ££’s and have patients interests and voice at the heart of service provision
- Could more voluntary organisations have stands at community events?

integrated working

Supporting those with chronic long term conditions – how do we maintain quality care and support?

- No particular issue to raise at the moment
- NHS changing so much, what will the impact be?
- Previous specialist hospital in Sheffield
- Concerns about using local services and external bodies/organisations
- Spinal cord injury – nearest unit (?) in Sheffield
- Only 6 spinal units in the UK
- Fortunate with past care
- How do I access services?
- How do patients' needs fit in with NHS changes
- Services are contracting (?) and changing
- CCG need to advertise what services are available and what they will provide
- Patient engagement groups' representation
- No local spinal specialist
- Lack of knowledge at practice level
- More information to be made available at Practices
- Christmas Maltings modern – no hoist – consider access
- Patient Group fundraising to purchase equipment
- Diabetes, heart disease – medical management (?). Community Matrons to support long term conditions/COPD
- Cancer Support Groups run predominately by hospitals
- Stoke Mandeville for pressure advice
- Locality Groups – people/patients need to be vocal and make CCG aware so that information can be shared
- For consistency have the same clinician
- GP to have close contact with Specialist

integrated working

Family/volunteer carers need support. How can we look after their needs?

- Support for voluntary/family carers, gets them ready to look after family and friends
- What support is offered?
- CCG have just funded 2 posts in the West to support this
- Respite advice
- Talk and support
- Health and wellbeing
- Young/adult carer support
- New piece of work in practices to identify these and carers
- Personal story – when lady came out of hospital in Sussex with disability (temporarily), family tried to help but needed specialist care
- Community nurse came to assist, not allowed to change dresses
- Unable to use crutches as had undiagnosed broken arm, despite reporting pain
- Community nurse only came once because the hospital that did the original operation was private
- What happens to those people who do not have family/friends and to rely on – where are the carers/care options?
- What is outside of the charities?
- Not a link between NHS services and charity services. The newly appointed GP advisors in the West should improve this
- Need to provide respite/transport as part of the 'carers' package – very difficult to cover all of these aspects
- Need to be more efficient
- Could practices have a 'help' area on their website to obtain advice of being a carer?
- There needs to be one phone number for all to access lots of data/support available – can the organisations come together and provide some funding together to get this implemented.
- Felt the carrier in GP surgeries is the receptionists who seem to decide why/when a patient sees a GP
- Patients expect GPs to be social workers/liaison between services – just want GPs to be GPs

- Cambridge have allowed carers to gain prescriptions, this is being trialled in Suffolk
- There is no clear definition as to who can give the carer respite – too many hoops to jump through.
- No flexibility once becoming a carer
- Lots of information providers no doers!
- People give up, it is too difficult to get results. By the time carers contact for support they are at the end of their tether and help does not come.
- Carers find when they need respite i.e. a care home for relative whilst they go on holiday – there is no planning and family members/carers do not know where their relative will go until very last minute. No way of checking credentials of care home, etc.
- Funding cuts – has meant people do not get the chance to just 'offload' get together with other carers
- In other continues carers are awarded for their efforts in a 'points system' so when it is their turn to need care they are given additional help.
- Often when people need assistance especially with a mental health patient – the police are the first point of call and the healthcare professionals should train the police with tactics of how to deal with these cases

integrated working

Not everyone likes or responds to medication. How can complementary therapy help the CCG meet their priorities?

- Can we present the evidence base to you? Needs to be models of health GPs understand
- Can we run some joint projects to develop an evidence base?
- Develop a “self-care” dispensing pad which includes therapies people can try alongside medication
- Practice research network
- Human Givens Bill Andrews led project
- How “professional” are therapists? Do they belong to a professional body? Let us tell you!
- The Doctors have the “power” and people listen to them as the gate holders of health
- Manchester Hospital commissioned a complimentary therapy centre – send patients for ongoing treatment alongside current medication, after operations, after chemotherapy.
- Live Well Suffolk – could we talk to them?

integrated working

How can we be sure that what happened in Mid Staffs isn't happening here?

- As an organisation, we should allow Healthwatch and communities to walk on to a ward and speak to staff.
- We shouldn't chase everything – a lot of good things are already in place
- Staff survey can reveal a lot about the state of an organisation
- Mid-Staffs has brought an element of paranoia in = but is helping us to take extra precautions
- Close minority of complaints
- Enough some people are frightened of complaining – think it will affect their long term care
- West Suffolk Hospital (WSH) has 2 internal patient surveys, though have to be courageous to complain when lying in a bed
- Next challenge in WSH has to save money – how can this be done safely?
- Patient's associate good care with staffing levels – thought this isn't the only factor
- We have various performance monitors to see if any correlation between staffing levels and quality of care
- WSH looks to volunteers with things like feeding – can free up nursing time.
- WSH uses 39,000 hours of voluntary time a year and tries to use volunteers in a complementary way where appropriate
- WSH working more closely with Suffolk Family Carers
- Sometimes a carer may want to take on some of the more personal care i.e. feeding
- Saving money –
- Looking at how Department of Health service could be run
- But a lot of the decisions aren't about saving money – but about sustainability and patient safety
- An example of safety is the number of procedures a consultant has to carry out to be skilled
- If there isn't enough clinical work to do, can become de-skilled
- Work to be done on improving prevention of care packages in community
- Can sometimes be a whole hand of people who don't need to be there, but waiting on care packages

- This has knock on effects around the systems such as the 4 hour waiting time in A&E department
- WSH talking to a company called Hospital at Home – where patients are still under the care of WSH and consultant, but patient is in their own home
- Joined up working is key – a lot of information about, but organisations need to talk to each other
- Need to breakdown culture of organisational/budgetary boundaries
- Something missing from part of joined up working is professional social care
- Involved social workers at the earliest opportunities
- Things Anne would look at if assessing patient safety:
- Patient experience
- Wonder around building
- What's in the press?
- Social media
- All gives an idea of themes
- WSH must talk to Healthwatch Suffolk and CCG and other agencies who gather information
- In Mid-Staff, lots of trends where coming through the LINk, but nobody collated all the information
- WSH needs to communicate to patients that there are systems in place to prevent Mid- Staffs happening

integrated working

There are at least 2000 people with learning disabilities in Suffolk and only 3 hospital learning disability liaison nurses in Suffolk

- Learning disability nurses training nurses to be link nurses
- How do they make themselves known to patients on a ward?
- All health professionals aware of issues of those with disabilities
- Person-centred care
- All treated as individuals

integrated working

How can we establish a person's needs in a time of crisis?

- What is a crisis? Anything that the individual sees as a crisis – mental health/equipment/care/etc
- Age UK are doing research on this in 2013/14
- Need to link the knowledge and information for all
- Contingency planning – bottle in the fridge? Does it still exist?
- How does the system know if there is support?
- Can the village have an infrastructure?
- Integrated systems stemming from GP
- We know crisis points as triggers
- Navigators for frequent users of service – reduced admissions
- Is there a leap back in from welcome home services to identify need?
- Fire services recognise need when seeing hazards
- Impact of environment – social coping
- Discharge planning key
- Cycles of need – demand – risk stratification – must have social/emotional/environmental issues
- Continuity of support mechanisms

integrated working

Neurorehab

- No statistics of incidence of acquired brain injury
- Whole group of people suffering – small number, high cost
- More than one million people living with traumatic brain injury in the UK
- Experience from elsewhere shows that 2/3 not traumatic brain injury, e.g. aneurysm, stroke, encephalitis rather than through road traffic accident.
- Not necessarily diagnosed as a brain injury
- Diagnosis often takes place at A&E as a result of an “event”. Misdiagnosis often because of ambiguous symptoms – heterogeneous
- Often diagnosed with obvious physical injuries and brain injury missed
- Symptoms very often not visible without CT or MRI scan. Not routinely done.
- Patients very often don’t recognise their own symptoms or the changes to their personality.
- Some young people end up as young offenders in justice system rather than being in rehab system.
- Research carried out by Exeter University on this show significant proportion of young offenders who have had previous blows to the head.
- Even minor injuries can injuries can affect mood and anxiety and tip people into mental health services.
- Long term neurological conditions, can people improve or recover with rehab input? If it’s a progressive condition rehab can ameliorate
- Voluntary sector organisations are especially good at advising people as well as campaigning and providing services
- Lack of investment into voluntary sector should be properly commissioned and properly funded. Should be added value rather than replacement
- Voluntary sector often falls on deaf ears.
- May be attainable business and need to be viable.
- How do we promote the needs of people who need brain injury support? How do we flag this up in the system so it can be addressed before it reaches a crisis?
- Need appropriate acute interventions and diagnosis, then long term stable rehab when no longer I need of long term acute care?
- In marketised system, everyone competing, should have clear pathway.

- Concern that once services go into the community then they dry up. What's the point in saving somebody if no care for them once they are discharged – often a question asked by families.
- Early investment in rehab can secure the system (public – sector wise) £££s in the long run and improves whole families' lives.
- To what extent is the CCG engaging with Neurorehab provider organisations. Feels that the will is there but nothing happening yet
- Pleased that patient experience is key priority for this CCG. If this CCG is really committed to patient experience then listening should lead to improvements in provision of neurorehab.
- Sometimes interventions only need to be targeted and short term, yet make such a difference to people's lives.
- Patient stories need to be heard by the governing body
- What worked, what didn't work (experience based design)
- How do we better link up services and volunteering. One individual gave example of medical conditions preventing her from cutting her grass at home. She wants to and her neighbours are unhappy but she needs someone to do it for her.
- Links with secondary services don't seem great. We need link to bring it all together. Personal budgets give individuals more control over what they need.
- Trauma networks have developed initiatives such as information prescription, empowers people. Also rehab prescription = social prescribing.
- Need way of doing for those that don't have mental capacity.
- Time limitation (12 weeks) on neurorehab stops the support at the end of the end of the diagnosis period. Understand the squeeze but what next?
- Lots of innovation and ideas in Suffolk that can be used and brought together
- If we get this right (1999 Professor Roger Wood research) result in cost of life saving = more than £1m per person if brain injury occurs in their twenties.

integrated working

Why won't hospitals employ eye clinic liaison officers (ECLOs) as part of their staff at point of diagnosis?

- Pilots have proven the success and worth of this early intervention to providing advice, sign posting to appropriate options of community services, voluntary services and statutory services.
- Patient surveys prove the importance of an eye clinic liaison officer and the fact that they can talk to someone immediately.
- Eye clinic liaison officer will supply information about all services available – totally unbiased.

integrated working

How to prevent mental health problems in children by working in schools

- Schools don't have good understanding of mental health issued in children – missing opportunities.
- If parents missing the issues – what can be picked up in school?
- Teacher fuels need to focus on other children not having these issues.
- Not taught to handle children with mental health issues/this is what psychologists are for!
- CAHMS – workshop every few months – trying to discuss what mental health is.
- Business/service commissioned to provide/develop cure. Need to look at prevention
- Questions: What would help?
- Answer: Need to influence parents – children not responsible for themselves
- Question: Over stretched schools – how can they be encouraged to adopt measures to help mental health issues in children?
- Answer: Looking to children – looking at their issues. How are they feeling today, what makes them feel happy?
- CAHMS – Youth Commissioner – wants to give young people a voice. Listen to their ideas, their journey. Where are the gaps in the service?
- St Benedict's – 16% leave – without 6th form. Children are disengaged. Processing psychotic tests – language awareness of their strengths, weaknesses, hopes, aside from academic topics
- Possibly borderline mental health issues, in high performing schools, minority leave, very low esteem.
- Work experience needs to be a programme (monthly?) to raise children's aspirations.
- Rate children's achievements – tying in personnel, discuss their work, and give aspirations.
- Articulate enough to contribute their ideas – develop their own projects.
- Trust (psychotic) helps identify needs – direct them to the school personnel, most able to help them.
- Increasing self-awareness
- Not easy to access schools to progress these ideas. Incentive: we want to help with your i.e. truanting children.

- Stricken curriculum: Personal Social Health Education (PSHE) Year 10/ not Year 9
- Need consistency and co-operation
- User led initiative: possible forum – child led within schools (weekly?)
- Plea: PSHE – spoken of over a range where no appetite can be shown.
- School councils – interviews, as well as head teachers, student voice is being listened to, on a range of topics. Part of power structure
- Suggestions – if idea for addressing mental health users was taken to school councils would they help us programming it?
- How do we improve overall health and wellbeing, why aren't we teaching them compulsory wellbeing, direct, how stress affects them?
- Taught in primary school how to look after themselves
- Experience: kids with mental health issues, difficult to engage, but once involved love it! (Exercise).

integrated working

Governance – why are private supplies of healthcare, e.g. Serco, not complying with statutory law – Freedom of Information Act?

- Public meeting held last week. Serco have taken over Community Services. Had loads of jargon in presentation
- Ruins nurse and community services
- Are providing NHS services but do not have to comply with legislation
- Serco do not have to provide FOI's (freedom of information) – sometimes sensitivity
- Serco hide behind this
- If an organisation is providing NHS services they should comply with statutory obligation
- Do have to comply with NHS legislation
- Way around CCG commissions the service – ask CCG for information
- If you don't get the data you're interested in then would it be available by the CCG?
- New territory for Serco
- If patients want that information then
- How many random FOIs questions a year from press private companies
- If you want to know – the contract with Serco means they have to comply with NHS legislation
- If they appear to behind this then it will give heated debates
- We had the feedback on the FOI and we are going back to Serco about this
- A whole set of performance indicators set by the CCG and will be monitored every other month.
- If patients and public have any questions about this, they will happily be answered
- The way Serco answered the questions last week did not give reassurance

- What is being done in terms of data protection and safeguarding?
- How can it be a fair service if Serco do not comply
- Serco could invest in technology to save time
- The admin system releases district nurse time to care for patients
- Do not want to have to take everything with them if they do not go back
- Up to the patient to be heard
- If patient uses private services and not happy then it's as they talk to:
    - To talk the CCG about services
    - Can I talk to private services? Yes
    - All complaint groups link up
- If the service is not right then tell the CCG so that we can commission the services
- Part of what the governing body will do in their public meetings is to look at complaints, carry out reviews and amend and announce soft intelligence from GPs
- Information Governance is an issue and focus
- Have given money to WSHFT (West Suffolk Hospital Foundation Trust) for electronic records
- Communications department came and told Julian Herbert (Chief Officer) – useful representative from the CCG. If another is done, useful to have CCG representation.
- Unfortunate thing appears to be the reluctance to make changes
- If Serco is less than NHS bids and invest – Serco considerably lower than previous spent
- Ensure to put services in and keep quality services we require
- Change systems so that district nurses can look after patients
- I use to work for the NHS – challenge to change. Not joined up services
- Interested to look at Serco and how they have changed

- Look at service lead reception
- Work/life balance – too much life
- I think it's heading to change for services in favour of the private sector
- Sold itself down the river for private sector
- The demands for NHS is greater than ever – have to look at sustainability of the NHS
- The CCG is trying to engage with the voluntary sector
- There is a problem that there is an older population
- Long way off from changing in the NHS
- Seen it getting witted away at the edges

integrated working

Joined up commissioning for neurology

- Rep – Epilepsy CCG Area Health team
- Neurological audit for Suffolk as East and West Suffolk are commissioned separately – audit to look at service user engagement. Joined up service would complement each other – does in need service redesign?
- Epilepsy – some members are on border of East/West and have difficulty accessing services. Whole of Suffolk should get the same service – e.g. one need social anxiety help and were put through to Child Abuse service.
- Stroke managed quite well but lot of other neurological issues not efficiently provided for.
- Need information earlier rather than waiting until crisis point
- More nurses need to manage prior to being admitted to hospital
- Epilepsy does NOT require ambulance all the time but after a seizure finds there is always one provided. Epilepsy information needs to be more open and accessible – need more mental health services, cognitive therapy sessions rather than psychiatrist. GPs have tendency to refer to psych. Seizures are not the issue, more living with the condition – lack of confidence to go out which would be helped by talking to someone, not sent to psychiatrist. GPs mainly don't understand the difficulty is dealing with this in between seizures.
- Being more transparent will help in knowledge of what is need for long term conditions (neurological)
- Holistic overview would help – look at the whole situation with more knowledge and awareness. Psychological and support is required.
- Concerns about services provided once discharged from hospital
- Should neurological issues come under mental health topic as not all one relevant under this heading?
- CQUIN targets for neurology would be beneficial
- Local targets are decided by health professionals – helpful to have service user involvement in deciding the local CQUIN targets.

integrated working

What is the CCG relationship with the clinical support units (CSUs)?

- Suffolk isn't the norm with its shared management team and way of working
- There are advantages but difficult to identify disadvantages.
- 2 CSUs have already ceased to be – there is a big risk if one CSU is servicing several CCGs and if one or more CCGs pull out it may destabilise the CSU.
- Why aren't more CCGs following the Suffolk model?

integrated working

What support can be provided for people who don't qualify to enter secondary mental health services? But one suffering mental health difficulties, which make day to day life hard and they need support

- Most difficulties when clients do not meet criteria to be supported by the mental health team
- Patients appear to be unsupported and float around the system
- Other support services already notify that individuals they work with are no longer being supported by care co-ordinators
- Suffolk Wellbeing Service – people can't be too unwell or too well – still cross section of people that cannot get the service they need
- LIDTs (Local Integrated Delivery Teams) new CMHT Pathway (2 teams – Newmarket & Bury)
- When service not provided do GPs know what to do?
- Attending Suffolk one groups but still need support from a 'medical model'
- Intervention services in place but people need long term support – also avoids them keep having to go back to GP surgeries
- Psychiatric services not being provided when needed – on medication but only link and medical professional – GP
- Positive support from voluntary groups but still gaps in long term and recovery needs
- Patients fall between the cracks in services
- Personality disorder – need diagnosis prior to receiving support
- More emphasis put on self-help and peer support (need support to get stable)
- Suffolk Mind looking to re-establish support groups (ceased as view that individuals were becoming dependant on service)
- If people are supported in the community they are less likely to use the services of their GP
- Issue highlighted where individuals and mental health move in and out illness
- Do professionals know about the support groups and other services available?
- Utilise GO surgery for sharing information – open days, etc
- Service Directories recognised as positive

integrated working

- Who is filling the gaps? Where services/funding has been cut to the voluntary sector
- Education need sharing regarding maintaining physical health and mental wellbeing
- CCG working in an integrated way and Suffolk County Council (SCC)
- Suffolk Mind – has availability – how is this information shared?
- Potential virtual levels of support- text/email. Initial sound base and decision as to whether intervention from mental health service required
- Were GPs involved in consultation with NSFT regarding the changes in mental health service delivery?

integrated working

What links are being made between children & young people (CYP), Suffolk County Council (SCC) and the CCG to analyse CAF/TAC data to identify children & young people and family needs?

- Need to improve CAF/TAC information which is available
- Need experience of how to tap into communities with young people
- Engage young people – use Facebook, social media forums
- Specific topics such as skate park
- West Suffolk – common assessment
- Sharing information and local people – across local authority and CCG needs to improve how data on children and families is shred
- Should vision of capacity and funds available to be worked up
- CAF access – low level need identified
- Personal experience
    - I was bi-polar and it would have been helpful if there have been available learning and awareness
    - Crucial to start early with children
    - In mind and physical body – not keeping yourself active not helping with up here (head)
    - What would be helpful – I was crying all the time and that was really good
    - Some aspects of behaviour could have been picked up on
    - PS framework talked about personal relationships and health and wellbeing
    - Healthy eating plays a big part
    - Breakfast clubs – ensure a good healthy breakfast, not full up[on fats and sugar. Therefore you're not pinging off the wall
    - Have been working with children in temporary accommodation
    - Suffolk Users Service – work with the emergency services

    Didn't hear much about children and school during the speeches

integrated working

How can we ensure people without access to computers are consulted and informed?

- There is the assumption that older people can access information via a computer or text messaging service, but often they can't.
- Principal service users are disenfranchised as they don't have access to technology, or patients might have a computer but only know how to use it for a specific use, e.g. to send an email, but can't do anything else such as search the web.
- The GP surgery is a place where older people have contact and the GP is a very powerful source of information for the older patient.
- Older people tend to do what the GP tells them
- Use the power of the doctor to relay the information to the patient
- How do we work with GPs to do this? Can a meeting room be used one day per month as venues for educational sessions on different conditions and the services available to treat them? Could the district council be involved? Patients don't know what services are available to them
- Can repeat prescriptions be a way of communication information to patients? Many older patients get repeat prescriptions and this a way of keeping them informed
- The information should be in large print and in black and white colour. Leaflets and posters are still useful to older patients
- Information should be available via a telephone number and not just on a website. The number should be direct to a person and not an automated services with lots of options as this can be difficult for a patient with dementia who forgets the phone options available to them.
- There is too much of an assumption that people can access the internet easily and there is a lot of bad information on the internet.
- Can we integrate young people as health advisors to help and education the older population?
- There are health issues related to using computers all day
- 111 service should be advertised on repeat prescriptions
- The older the person, the less access they have to services
- We need to engage with patients in as many ways as possible
- This is not just a problem for the NHS – many companies now provide a website rather than a phone number
- How do we get information to patients who are isolated in rural areas or who have no friends/family support?

- TV/Radio to advertise services. Could an elderly exercise programme be played on TV, for example for 10 minutes, for a popular afternoon show such as ‘Countdown’?
- The government agenda is digital by digital by default which is exclusion by default.
- Do we teach older people how to use computers? What about elderly with arthritis who can’t type? There are older people who want to learn how to use a computer but also a lot who don’t/ should we have a ‘hub’ where older people can access technology without them having to set it up and maintain it in their own home?

integrated working

Could we return the out of hours service back to the doctors instead of the service formed out to completely disassociated body the young and old need a familiar face?

- How could we get local GPs running it again?
- People avoiding OOH and going to A&E
- Can CCG pressure GPs?
- Problem – There aren't enough GPS, those in 60-65 bracket are retiring
- Could GPs open for emergency appointment on Saturday and Sunday appointments?
- They could access patient notes. Could we thin out the weekly service to enable the weekend working?
- Can we shift the £££'s from A&E/Ambulance to GP OOHS?

integrated working

How do we promote awareness to this health care service to better support and look after their support needs (learning disabilities)?

- NSFT is the host for learning disability staff?
- In summer restricting
- Narrowing down – only seeing learning disabled people with mental health problems
- Only seeing people they are commissioned to see
- What NHS staff will see these patients with learning disabilities?
- In the future:
- Sometimes they worked very well, other times not
- Severe learning problems, autism, not care which cannot be delegated
- Support has been cut significantly
- Learning disabilities Liaison nurses now employed
- Quite lonely for patient with learning disability
- Better awareness amongst organisations
- Universal documentation/communication
- Awareness for staff
- Money for support workers spread very thin
- Left to fundraising
- West Suffolk – 3 teams of specialists – now part of Mental Health Trust
- Learning disable without mental health will not be treated under new criteria – only see mental health and challenging behaviour patients who will be vulnerable
- We (Public) are not being told
- NSFT 30 day staff consultation
- CCGs got a development group together but put on hold
- NSFT are merged through commissioning and contract route
- NSFT new structure – no remit for physio's
- Commissioning discussions would like a steer in what I say in my care plan (NSFT physiotherapist)
- Not being patient led, service lead
- Learning liaison nurses have made a tremendous difference in hospitals

- Staff training
- Passport information – who can pull these together?
- Finding ‘pot’ for extra support
- Support workers have to go into hospital to support the person

integrated working

Carers for patients with mental health problems; how do we support them?

- 2 family carer groups shut down in Bury St Edmunds and Brandon
- CCG shut them down – said they surveyed community. The survey didn't make it clear that groups would be shut down
- Set up the education groups (by Suffolk Carers) to support carer but not same group (will set up social/peer group)
- Have written a letter of complaint
- Occupational Therapists (OT) input into carers to support with practical techniques
- Groups shutting down – losing social support
- Sudbury group continuing volunteer group
- Information on changes needs to be disseminated
- Costs – staff, building rent
- Money diverted to education groups – criteria for money changed
- Mental health patients don't feel confident asking for what they want and carers do know
- Cross-country carers – carer lives in Cambridgeshire, family/patient lives in Suffolk – carer can't access call centre for support
- Support groups closed in Suffolk Mind
- Funding should be directed by community needs that should be criteria
- Assessments should include resource for support as a carer – education, etc
- Carer has no after-care support from hospital. No hospital transport to visit husband – huge impact on carer. Carer becomes a patient – prevention orientated commissioning.
- Doctors need to link CCGs as primary, 'front door'
- Change of thinking – GP sees patient, prescribes carer rather than calling
- Commissioning voluntary groups for carers
- CCGs much better than PCTs at engaging
- Patient practice groups not acting as they should – just a 'tick box' exercise, some very good though
- Some are only online – excluding patients
- Not interested, missed opportunity

- Engagement has been lost – over the phone only, no interaction, people power lost.
- Good for other counties to be joined up
- No fuel payments across country
- With ASD (autism) patient doesn't want to travel via taxi, will go to service if carer drives but no fuel repayment
- And specialist does not want to travel
- No joint up approach across counties
- Carer with multiple family members who need caring
- More support for physical (not mental) carers as well
- Carer having to use own resource (cleaning lady) to act as a carer
- Informal peer group support rather than education. Just provide a room for that (support) to take place
- Volunteering is fine – just keep the principle
- GPs need to know about social drop –in groups
- Confidentiality issue for carers - GPs can't let carers know because confidentiality restrictions. Send a statement to GP of carer situation (alternative option)
- Carer trying to gauge her responsibility from specialist for information on responsibility
- Amount of money for caring is insufficient £0.30/hour

integrated working

Out of Hours

- Need a clinic in Thurston
- Need a familiar face
- Need access to notes – real benefit may deter going to A&E
- Could a group of practices come together to support out of hours
- Yes if records are accessible
- How can we improve the out of hour's service we already have
- Making use of GPs who work part time, i.e. those with your families
- Making use of GPs who have taken early retirement
- Renegotiate contract with GPs regarding out of hours service to give them more incentive to take ownership of the service – thus saving expense of e.g. ambulance service and emergency admissions
- People don't understand how the workings of out of hours – A&E gets overwhelmed
- Need greater publicity of 111
- Need extended awareness of GP services
- Patient complaints at WSH in waiting times at A&E
- CCG needs to put pressure on member practices to improve GP access
- GPs should take back OOHs – give continuity of care
- Travel distance is too large for Harmoni's provision
- CCG should begin to debate with members around OOHs
- Weekend working needs to be introduced as a concession
- People avoid OOH and go to A&E
- Should the CCG pressure GPs?
- Problem – there aren't enough GPs and those in 60-65 age brackets are retiring
- Could GPs be fed up from bureaucracy to release time for OOHs?
- 3 weeks for routine appointment
- Could GPs open for appointments on Saturdays and Sundays?
- They could access patient notes
- Could we think out the weekly service to enable the weekend working?
- Can we shift from funding from A&E to GP OOHs?

integrated working

Engagement with the voluntary sector

- Don't understand how the CCG liaises with other departments/trusts on what they are supposed to do with liaising with voluntary sector
- How do we spread the message? Where are the links to connect people and how do we know who they are?
- Are they proactively seeking out the different voluntary sector organisations?
- We don't know what we don't know
- What about a dedicated role for this?
- Which 50 organisations are involved in the neighbourhood teams?
- Do health professionals see the voluntary sector as inferior service?
- Directory of Services – keep in electronic format (? on a website) so can be kept updated
- Invite voluntary sector to include them
- Voluntary sector page on website
- Develop relationships with practice managers
- What about a public pin board (? Virtual) for patients to recommend voluntary sector?
- Posts can be removed if an organisation shuts down
- Can be managed by network post
- How does CCG link with the voluntary sector at a strategic level?
- What happened to VASP?
- Difficult to engage health professionals with strategic meetings/boards that are non-health

integrated working

How can we integrate substance misuse services to ensure appropriate use of services?

- More prevention to avoid crisis
- Prescribing
- Dealing with emotional needs
- Remove stigma attached
- Perception – lots of functioning people who have problems
- Over use of prescribed medications - not always obvious to others
- Are “repeat offenders” known/monitored?
- Family support and after care
- Support
- Day programme/residential
- Work with family of client
- Records shared with GP for referral discharge
- Care manager is main point of contact
- Record of long term outcomes?
- Random testing
- Honesty and trust
- Accessing help is a problem. Difficult to navigate if people can’t easily they won’t try
- Transport to the right locations at the right times
- How to engage these people?
- Waiting lists put people off, strike whilst the iron is hot!
- Realistic time frames – manage expectations
- Waiting times cause relapse
- Point of contact for support whilst help is sorted out
- What is meant by the term recovery? – clean from all substance? Or free from substance of choice?
- Medication managed by carer who visits for does to support
- Remove temptation by residents not having substance of concern on site
- Liaison service from point of admission to hospital

integrated working

Accident & Emergency at West Suffolk Hospital

- Invest in West Suffolk as much as possible.
- Too many people calling an ambulance
- Car parking problems
- Length of visitor's time if they move away to another hospital, e.g. Addenbrooke's/Ipswich

integrated working

Hospital Transport

- Patients decline hospital transport because call centre staff ask a series of questions
- Hospitals not providing best information – cheapest alternative options/?/consistency
- Information coming out of hospital for patients on hospital transport needs to include
    - Choice
    - Cost
    - Correct telephone numbers
    - Frequency of attendees at hospital to be included
    - Compromise between cost savings
    - Patient pays (how much?)
    - Demand on services
- Patients not attending hospital because of the cost of treatment
- Impact – cost & health – on long term health of patient
- Compromise between core savings
- Patient pays – how much?
- Demand on service
- Patient transport – issues
- Better information to patients who declined transport (why and ring of options/costs available to them with correct phone numbers for all providers)
- Clarity on information/eligibility of services offered to patients (recognise that some patients circumstances change)
- Need for better communication between hospital and voluntary sector
- Age UK – happy to coordinate and work with hospitals to improve information available

integrated working

West Suffolk Hospital Challenges

- **A&E**
- Have they enough beds?
- Is A&E design fit for purpose – built for population of 30k?
- Car Park
- **Pathology**
- Will the redesign create space for en flows?
- Could Wedgewood move?
- Will the personal relationships between WSFT & GPs be lost – hidden cost?
- Will it take longer, e.g. A14 more distance?
- **GP**
- Booking appointments
- Ambulance Response times & A&E
- People avoiding calling 999 or going to A&E because of state of…..
- Question the ability of EEAST to understand local XXX can we have a Suffolk system?
- Concern people are not going where they should be because of delays.
- 111 Leaflet – implies to go to A&E first?
- Culture of using A&E as first resort – especially with children
- Front door diversion
- WSFT and Harmoni aren't working well together

integrated working

General discussion about health services

- Expectations of health service are very light but the bureaucracy built around it to manage demand can actually be constraining
- Lot of people in the CCG are the same as the PCT so what's changed
- Health needs to be more pro-active and not just pick up the pieces
- Voluntary sector is brilliant at driving preventative care we should learn from them in health and redirect resources accordingly
- Friday and Saturday night at A&E called "the black shift! Because most people going there are suffering from self-inflicted issues, often driven by alcohol
- Needs strategic direction from highest level
- Need to be clear that NHS can't do everything, so how can we engage with voluntary sector
- Voluntary sector organisations have their own networks so can support the CCG with its endeavours
- Gaps in communication need to be tackled
- WSH (West Suffolk Hospital) audiology department won't include information for patients on free service to support people with hearing loss in their letters to patients. Don't understand why when it's beneficial to patients
- Suffolk Mind try to provide services that aren't available on NHS to complement services for patients, so how do we get listened to? Voluntary sector is innovative and responsive on a shoe string
- Help people to manage their health and stop using health services so much
- Voluntary sector feel they haven't been listened to for years!
- Appreciate how busy health workers are
- Services come and go so how do we keep on top if it? There is a role for a directory of services – very useful for health professionals
- GP lead for specific clinical workstream to go out and meet all the relevant and voluntary sector organisations, as Dr Andrew Yager has done with cancer.
- Voluntary sector should be an equal partner so how can it be engaged in redesigning services
- Voluntary sector organisations should all make contact with hospitals, PALs team as they often direct patients to those that can help

integrated working

Open Space Feedback session

- More events please – lots of subjects discussed but not enough time
- Can we have the villages in alphabetical order next time
- Funding pressures is a concern in all areas but what other resources do we have that can be used?
- Very energising
- A please to be a part of today
- Would like to say I am glad I live in Suffolk
- It's been wonderful – shows how many people want to have their voice heard
- Really valued todays experience
- Exciting that ideas might be put into practice
- Hold meetings in other locations for others to access
- Changes over the last year have been noticed
- Round to say we came up with the ideas
- Enthusiastic debates
- Good way for private and alternative therapy to engage with nhs
- Ideas with feedback on what has happened so you don't feel like no one is listening
- Good to have a voice and place to be heard
- Education, prevention, choice – join it all together
- Lots of useful ideas
- Realised problems are in rural and urban areas
- Did not want to come but glad I did as a service provider and user
- Out of hours care
- Excellent event for putting ideas forward
- Jargon and acronym heavy – simple language next time please
- You are the CCG that listens – well done

integrated working

Questions raised but not answered/notes taken

1. Departments and voluntary sector – who agrees?
2. The role of promoting happiness in healthcare for people with dementia and their families
3. Improving out of hours service to prevent A&E being overwhelmed
4. Improving provision of A&E and other emergency services so people can be dealt with more quickly
5. Why is Ipswich Hospital Trust not on the list of providers?
6. When I have tests done I want to know what they are and why they are required and what the results are
7. How can we make patient representation in GP practices more effective?
8. How can we access IT to combat loneliness?
9. How are staff being told the CCG news?
10. How are we working together to provide transport for people to access health services?
11. Millions of us Britain's choose CAM (complementary alternative medicines) as their primary health care. How can these be integrated into health care in West Suffolk?
12. How can we ensure there is adequate support in the home to ensure people with dementia stay at home longer and avoid blocking hospital beds and early admission to care homes?
13. What links are being made with local schools to improve childhood health and wellbeing?
14. The relevance of PPGs