Diabetes Event Feedback

South Holland Event

Positives	What could be Improved/Negatives	Ideal World Scenario	Improving Self Management
Access to Diabetic Nurses at QEH is good.	GP Practice woeful at diagnostic just refer " Fully booked" in an emergency	Free exercise at clubs	PDAC/ Daphne Courses = more classes and an evening class/weekend classes for people who work (have to use holidays from job)
Happy with care from GP - Community - Secondary Care	Just somebody - only receptionist	Regular checks once diagnosed	No guarantee of pump after PDAC
Type1 - Carbohydrate Counter - provided by hospital very good	Make carb counting part of diagnostic conversation	Nationwide screening	Blood Testing Kits to monitor and extending education 2 new diagnosis
Retinopathy Service (Mobile Unit)	Over a year to get on a course	Free Podiatry	Care homes/HC etc diabetes trained
Finger prick machine provided by diabetic nurse	Assumption that CP has already told you i.e Change regime	Social support for people with need such as footcare	People's regimes differ hugely for examples: P'boro couldn't believe amount insulin patient on (from Boston)
Excellent Child Specialist Nurse (Type 1)Support, Signposting	Find things out in ways you don't want	Mobile/drop in diabetic unit (local)	Lower No of Diabetic consultants - why is this ?
Excellent Diabetes Practice Nurse (Type 2) x 2 Appts per year	Conflict between Primary and Secondary Care	Designated Nurse /GP	At one point patient had consultant + Diabetic Nurse in appt to discuss management of insulin - very positive experience
Auto email appt reminder	GP emphasis on Type 2 (Funding for GPs)	Best Medicine not the cheapest	Ready access to a nurse (with skills) would also support and services in local area, fewer appointments with more services at one point in time
Sufficient back up for Diabetic Type 1 with early onset Alzheimers	Responsibility of patient/self control	More dieticians	Test Strips - enough available
Diabetic Nurse / Clinic at Practice	GP practice not knowledgable	Food labelling	Access to footcare
Delivery of drugs to home	System does not support people who can't help themselves	Healthy Living Centre(P,boro) need something like this in South Holland and Welland (Specialist Services and Specialist Consultants)	Diet Advice
Seen regularly at surgery/ see the same person and build up good rapport	What if not capable of complain	Diabetes training for all clinicians - mandatory training	Directory of services - in GP Surgeries
Excellent Child DSN at hospital	Travel to dialysis	Actual service support not leaflets	More access to spotlight courses - inform people about spotlight
Retinopathy Service (Mobile Unit)	Assumption of older people 'down to age'	More resources for individuals i.e. strips /pumps etc	Better Food Labelling
Excellent DSN	Individual treatment at GP Practice	Local services choice to go where work/where live - later services in the week/ evenings and weekend services	Portion Plates and measuring spoon
Service available at GP + Relationships	Information flow early stages	Better access to podiatry, eyes etc	Carbs and Cals Apps (cost involved) + Book
Carb Meter (Pre -Pump)	Lack of standardisation	Better referrals to MH some people get depression etc	Knowledge - detailed on what are the do's and don'ts
Good GP Practice (Type 2 for 10 years). Annual Check Up at clinic	Info/notes not shared across boundaries	Better/Quicker waiting times	Timesulin - Timer that fits on top of Novopen and counts how many hours since you have had your injection and resets itself to zero -(costs £40, Battery lasts a year)
Retinopathy Service (Mobile Unit)	Used to have 2 appts a year - now 10 all over the place (more local and together)	Education extended to Business (Time off for appts)	Test Strips - enough available
(Type 1) carb Counting and Check Up by switching GP Practice	Better training for clinicians regarding diabetes (across the patch)	First Aid Training - better education for diabetes	Sharing experience community or other groups (facilitated) Promotion Profile for events/info etc
(Type 1) Pilgrim Diabetes Nurse Good. Direct Access esp emergency	Coming round from general anaesthetic ask patient for amount of insulin - should know(patient had op)	Choice of pumps not told which one	Make people think about themselves
Retinopathy Service (Mobile Unit)	Had to do own injections at Fitz & PCH, didn't know amount/pen use	Limbs (injecting) can cause lumps etc - would have to pay to remove - should be free	Contract with diabetes team, know how to help the team that are helping you
Carb Counting	Bostonian - GA left on insulin and given no glucose (no checking) had to ask repeatedly for glucose - no check 4 hours (stopped breathing + resuscitation)	A prescription that flowed	Carers access to information
Johnson Hospital - Sorted IM balance	Insist they "know best" clinicians	Consultation of redesign within diabetes care (esp insulin pens	Get rid of message Boards on Diabetes UK Website (context/ mis information re: Treatment)
Retinopathy Service (Mobile Unit)	GPs and nurses Munro/Beechfield and Abbeyview - need education	Better support and groups/events on diabetes	Full information on diagnosis
Good written information from Johnson Hospital	Don't always have copy /info of scripts on person go to hospital no meds given	Local Service of Top Quality	Software application share Re: Calorie Counting
Blood Department - very good	When need scripts from GP not always helpful and on time	See consultant/high trained nurses	Be careful with information, don't generalize (Carb Counting, Food + Other glucose factors
Moved from Boston to Peterborough care 100% better	Education courses not consistent	Chiropody service -free/local - regular checks	"The Balance" (Diabetes Uk)
GP/Johnson = good service, sees consultant at Johnson	Doing PDAC at Mo Boston not offered PCH yes	Retinopathy local service	PHB Childrens Team brilliant - followed from hospital 2011 to home (dietician, consultant, psychologist, diabetic nurse) Seen at home within 24 hours
D. Nurse does return calls in spalding	Footcare: If have emergency wiped off list	Initial education programme	Needs signposting/Education
Healthy Living Centre (Pboro) : Good diabetes service	Poor transitional services	Every 6 months + access inbetween routine - more if there have been changes	Psychological Support
Gosberton has excellent nurse has diabetes	Individual treatment at GP Practice - lack of	Raise profile of diabetes + differences between 1 and 2	Individuals need to take responsibility for own care but needs the tools to be able to do this e.g monitors/strips
Induction when first diagnosed/Spotlight Induction	Being asked to self-manage of hospital when not appropriate	Cheaper Gym membership/swimming etc	Enough Test Strips
Complaint handling	Training of staff	Access to weight management clinics	Enough Test Strips
Retinopathy Service (Mobile Unit)	Written info from Johnson Hospital	Mentoring schemes - funded	Reminders re meals
	Boston pre and post op care	Riding therapy centre for children newly diagnosed PEDS (Ponies Educating Diabetics + their siblings- in Surrey) I will run it!	Timesulin (novoecho) - reminder re taking
	Podiatry (lack of) x3	Access to best/most up-to-date equipment	Good initial education (or any) x2
	Test strips - sometimes surgery not got enough in	Communication	More access to education - weekend/evening session and more regular
	Drugs - short time for re-ordering drugs	Technology - best available	Encourage community to share experiences - Peer
	Unhappy about nurse making changes to prescriptions	Using local facilities & enhancing not having to travel to pilgrim (puts stress on people)	Individual responsibility - lots of info out there
	Concern of quality of training of diabetic staff e.g nurses	If have to travel - a service that is easy, cost effective, has a support service	Reminders (Tools)

Positives	What could be Improved/Negatives	Ideal World Scenario	Improving Self Management
	Regular check up of feet - free? Not had feet checked	A centre for diabetic care	Testing Strips (Access & Quantity)
	Not seeing a doctor during the year - only seeing nurse	More quality control in GP	Spotlight
	Lost a direct contact which had had for many years via hospital which was supporting	Consistent person to look after you	Diet advice (what not to eat - Induction guides)
	Not all Drs have the same approach, treatment can be changed	More time with clinician (wait long time to be seen in a few minutes)	Advice Line - call anytime to ask for advice
	Footcare is all chargeable - £30 per treatment one appointment per year would help	End to "rationing" of test strips (box of 50 at a time not enough) 6/7 times for carb counting	Hypo Awareness
	Pre + Post op Boston Hospital care very hit and miss	GP taking consultant prescribing advice	Record Booklet (to track trends/changes to make patient more aware of triggers etc)
	4-6 weeks to see diabetic nurse - at last visit	Where infection presented automatically add more test strips as needed	Individual dietician plans (specific/individual needs e.g allergies to some recommended foods - what do they do)
	Time to get appointments - waiting too long	Pharmacy in practice to have adequate supplies of meds (insulin)	Clubs/meetings -peer support & advice
	Podiatry (lack of services)	Access to services/supplies facilitated elsewhere (Boots service)	Good initial education - diet/exercise
	Appointments cancelled (Acute)	GP Surgery (vary greatly, need specialist in diagnosis and care	Knowing potential complications
	Early diagnosis routinely	24 Hour access for expert help and support	Knowledge of employers + in the work place
	Stigma - Type 2 (national campaign)	Diabetic hotline for emergencies (e.g waited for 11/2 hours for ambulance, dr not equiped with glucogen)	Footcare
	Type 2 - not seen in community but seen in GP Practice	Access to services for diabetics e.g Chiropody	Access to - telephone initially expertise
	Lack of footcare locally (podiatry)	Education courses (available locally especially when 1st diagnosed	Pro-active professionals
	Negative experience in hospital - lack of expertise available at weekends in hospital	Support for children in school	
	No information on diabetic ward about hospital food - Carbohydrates /nutrition (QEH)	Stem Cell research	
	Lack of support nutrtional	Continuous glucose monitoring/pump combined	
	Diagnosis by GP of Type 1 - missing vital signs	Footcare every 2-3 months	
	Breakdown of service - retirement of lead clinician	Always see specialist GP and Nurse in good time	
	Lack of continuity	Directly contractable -email answered in 4 hours	
	Poor service when transfer from child to adult services	Enough Test Strips for Self management	
	Reduction in staffing levels at PHB (last 3 years)	GPs to have high level of knowledge	
	No cohesive service	Info to be given when diagnosed has to be very high quality	
	Seeing diabetes nurse in/venue consultant at a different venue	Diabetes UK website excellent, some websites give poor - dangerous information	
		Longer appointments - for better conversation	
		Local Diabetes group to have more support from GPs surgeries to promote local events	
		Insulin Pump (Type 1)	
		Insulin Cooler	
		Local Dialysis Service (South Holland)	
		Food labelling (portion size)	
		Standard pack of information for each type containing - Whats available,	
		Where and what resources/support is available	
		More expertise in Maternity Services - Diabetes Specific	
		Refresher course - Managing your condition	
		Regular monitoring when first diagnosed to prevent complications	

Welland Event

Positives	What could be Improved/Negatives	Ideal World Scenario	Improving Self Management
Good access to GP Practices and GP for Diabetes care	No preventative information for people with pre-diabetes	Preventing Diabetes - Better services for pre-diabetes	Structured Education-continued (face to face group sessions) - What is Diabetes, Connect with other diabetics, How to manage diabetes, Dose adjustment/dose levels
GP Practice good at monitoring diabetes and refers to secondary care PSHFT when needed	More information needed for children with a parent that has diabetes	Help with weightloss	Carbohydrate counting course and the best way to apply,
Continuity of care	More information for carers of all ages	Access to gym/exercise	Advice on changing needles and frequency
Sometimes good discharge outcomes by following up with community nurses. When elderly patients are discharged from hospital.	More specialist nurse input	Call in Centre dedicated to Diabetes with specialist nurses, retinopathy, dietician, podiatry (everything in one place / all checks done at the same time including consultant	Reminders to take insulin - i.e text messaging
Retinopathy Screening - referred if needed to hospital for monitoring	No access to dietitician	Community transport for those with travel issues	Diet sheet for pre-diabetes with each of the food groups and how they impact on each other.
Seeing the same person each time (ask)	No central point with dedicated diabetes services i.e Retinopathy , specialist nurses (Excellent facility -dedicated diabetes centre - Norwich)	More education (continued education) - What do the measurements mean, A card with conversion for blood results (old measurements to new), Carbohydrate counting	A self-help checklist with parameters and pit falls
Everything works well, same person - saves re-explaining	Geography -	Psychological Support	Set yourself a good -target/incentive
Telephone number - direct access (Pboro)	Hasn't seen Dr more than once in 12 years- no review of diagnosis? Is he selling himself short by lack of service	Education Courses	Raise worries with professionals - long term issues
Service is working - keeps me in good health	3 Drs seen over a month missed Diabetes - nurse picked it straight up, drs didn't know what to look for	Plan for the needs of individuals	Understanding what the long term disabilities are/could be photos-stats
Ease of access via telephone to specialist nurse (always calls back) which is important when you forget things	Under 2 teams (GP nad PB Comm) but although hyperglycaemic no one is looking globally at issues	Would deliver all of the 15 healthcare essentials	Just because you feel "well" it doesn't mean everything is ok
Good basic information (Sheepmarket)	Diet Nurse - not much use - was going to email info but didn't, didn't understand pulses etc also 2nd appointment still no follow on (Builder with packed lunch)	Access to dietician	You are told the negatives of not controlling your health but not the benefits if you do.

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	Under resourced at practice - long time to see specialist nurse when to practice end of July -		
During your MOT/Blood Tests the follow on is very good	appointments kept being delayed. Seen new years eye (St Marys)	Peace of mind that the service I am getting is the best quality I can get	Public understanding and judgement
		Personalised approach - not just go on a diet - but longer term 'customised'	
Dietary info from nurse is very good	Conflicting dietary advise by deficient nurses	help strict diet with monitoring	Include partners/family members to encourage you
Seeing same person - continuity	Always sent to WWW……	Extended time to get further information regarding change of lifestyle	How feel today nay change - ongoing support
Retinal Screening	Don't set targets for bloods	Cure	Setting targets personally as an incentive
Access to GP's and care - immediate access to nurses	Better communication between professional	More thought to multi-meds	Access to education courses + refresher courses - What is diabetes
Being able to ring - diabetic nurse (vanessa)		No tablets	Education - What is diabetes, dose adjustment, changing needles, has to manage
Deepings + Little Practice - immediate access to diabetic nurse - Open			
access policy	More thought given to multi - meds	Weightloss - regime especially for people with diabetes	Test machine + Test Strips for testing
		Information on "Food" goods that you buy aimed at giving people with	
Able to get hold of someone when needed	Not enough support with the complications of diabetes	diabetes correct info - hidden sugars	More info in all areas + ongoing
GPs ringing proactively	Specialist Doctor not listening to patient	Lists of good food (when you have diabetes and lists of bad foods	Support groups
			Peterborough PDAC- learnt a lot 21/2 days (would have liked sooner after diagnosis
Retinopathy van very convenient (walking distance) + quick	Being pumped full of more and more insulin with no effect	Referrals to out of area specialists	most useful - offered through diabetic nurse
			Hasn't been offered a course and thinks it would be useful - currently uses guess
Retina screening is now better	Dietary advice - personalised specialist dietician not much help	More personal responsibility	work
		Everything under one roof - screening, podiatrist, dietician etc - local, fully	Support Groups - not financially viable when paying for a hall (with 5 people) - but
First diagnosed education event very good	Issues re: Diabetes nurse, understanding equipment + access	staffed (specialist)	keen to see them happen - more marketing?
			More information needed in all areas - not having to travel to see people, sooner
			after diagnosis, with other conditions, need more information to be able to manage
15 patients is covered by St Mary's on review	No hub for services	Better access to footcare	multiple e.g professional or someone in the same boat.
Sheepmarket - very good (specialist nurse (organised with appointments		Option (choice) to see a dietician expert immediately after diagnosis and for it	Support groups - hard to get specialist nurse/dr . Hard during working hours. Were
and very good service	Chasing appointments for regular checks	to be a positive experience	very helpful when they used to take place
Type 1 = Equipment etc good no real problems	Would like more frequent foot checks (Podiatrist) used to be seen twice/year	More understanding of active lifestyle	Outline - Opportunity to share experiences
	Retinopathy waiting list very long or got to travel further if appt missed or newly		
Nurse will respond if needed when call surgery	diagnosed - more flexibility needed	Have a diabetic nurse come to you - if can't get to centre/GP etc	Everyone should be able to access Daphne/Desmond Education Courses
	Peterborough - having to chase appointments for more regular eye checks (used to give		
	appointments when you were there.	Early evening appointments would be useful	Refresher Desmond/Daphne Courses
	Hospital food - not seen as a priority for diabetic patients to give you what asked for/		Oakham practice = gave a booklet with info but also could add your own notes/self
	indicated would be provided	More people trained in insulin pumps so no need to travel	management
			Type 2's Especially with 1st diagnosis should be able to test sugar levels to see effect
	Not enough information/advice on hypo's etc when first diagnosed.	More research on pancreatic transplants	food has
	Specialist nurse from Grantham no knowledge/ relationship with consultants at PSHFT	Reminders to appointments , Text messaging/call etc	Access to courses evening and weekends different areas (where yoiur consultant is)
	Better access/education dieticians (access to specialist dieticians)	Access to wider range of different medication	Regular visits to a podiatrist
	Diabetes Nurse attitude doesn't know anything about insulin pumps so don't ask	Local hospital (+community hosp)	Reduced fees for keep fit/exercise
	Target sugar levels - changes/ consistency (ex used to be '7' now 40 = self management of	All practices (GP) nurses banding together to run special local clinics and	
	services	more of them	Financial support with new glasses
	Clinic access generally	Better education for all nurses	
	Retinopathy van screener in van didn't listen - disregarded patient view - more patient		
	understanding.	Phone for an appointment and get it straight away	
	Psychological support - not there for newly diagnosed people.	More education for retinopathy screeners	
	Not always been recalled to retinopathy	Better access to Psychology services	
	Lack of education of staff in clinicla settings	Ban all food specific for diabetes	
		A nice consistent blood sugar level, esp if you eat properly	

Other Comments:

Booking appointments Peterborough City - admin errors booked into wrong appointments laser surgery/gen check up mixed up. Hospital notes filed under wrong name! So no follow-up appointment given. Hospital notes marked as being discharged from eye clinic by doctor following appt - that never actually took place, resulting in extensive laser treatment a heanorrhage in both eyes.

1973 No support or help - readmitted 10/7 later!