



Patient choice in growth hormone prescribing: The Nurses' perspective

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Introduction

- What influences choice
 - Pharmaceutical companies
 - GH support systems
 - Devices
 - Patient choice
 - Nurse / Doctor
 - GH indications
 - CCG
- How does choice work
- Nurses' roles
 - Concordance
- How can we enhance the choice process

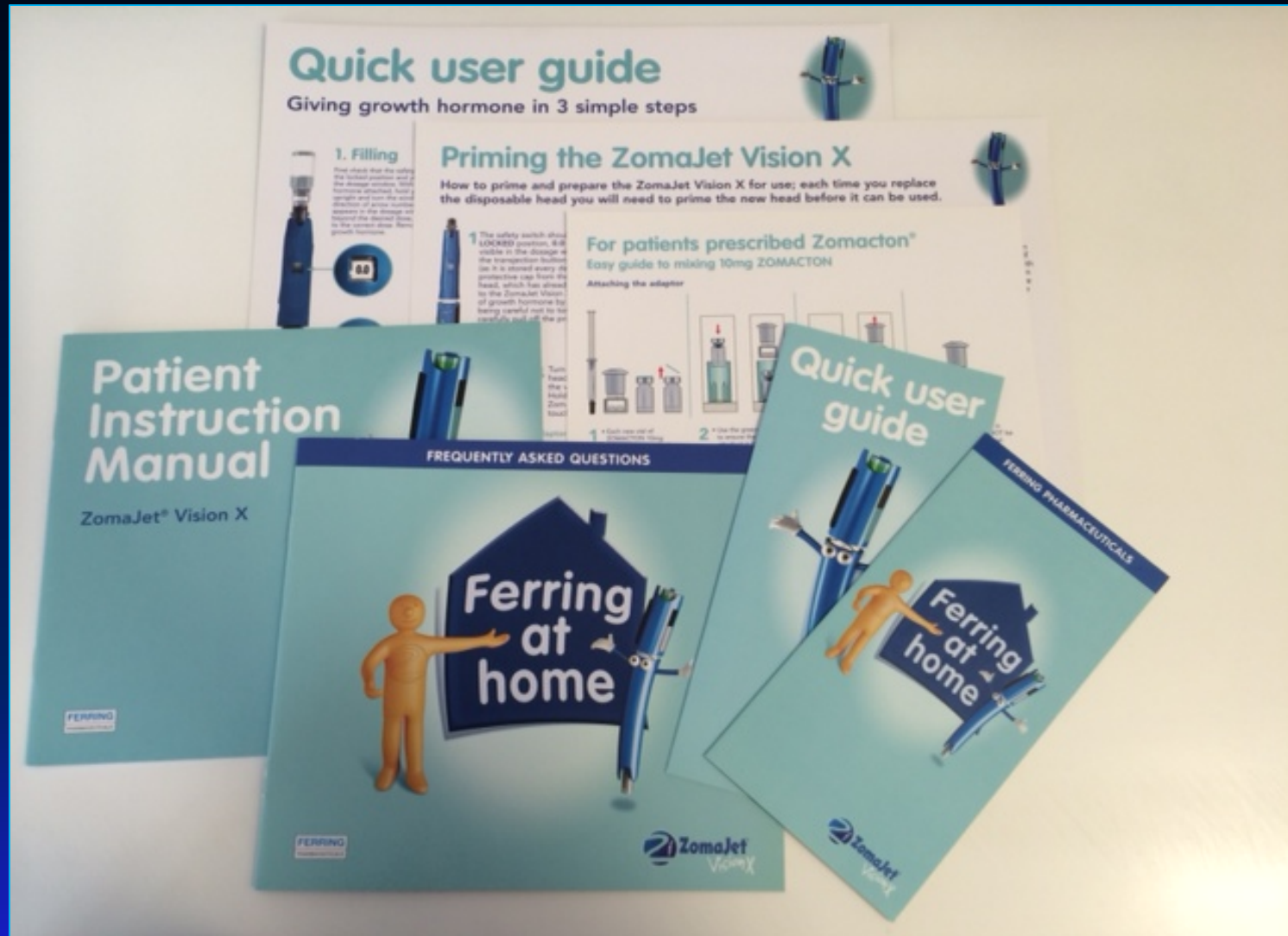
GH Support Systems

Company	DVD	Literature	Home Nurse Team	Dedicated Nurse Team	Helpline	Drug delivery	Text reminder	Download info
Lilly	✓	✓	✓	✗	✓	✓	✗	✗
Ferring	✓	✓	✓	✗	✓	✓	✗	✗
Ipsen	✓	✓	✓	✓	✓	✓	✗	✗
Novo	✓	✓	✓	✓	✓	✓	✗	✗
Pfizer	✓	✓	✓	✗	✓	✓	✗	✗
Sandoz	✓	✓	✓	✗	✓	✓	✓	✓
Merck Serono	✓	✓	✓	✓	✓	✓	✓	✓

GH Company DVDs



Ferring booklets



GH Company booklets



GH Company booklets



GH additional support

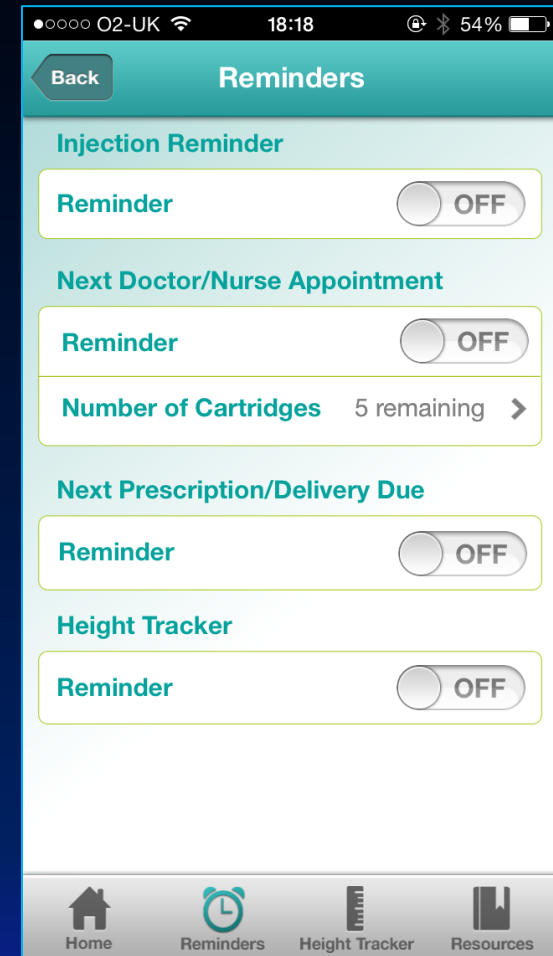
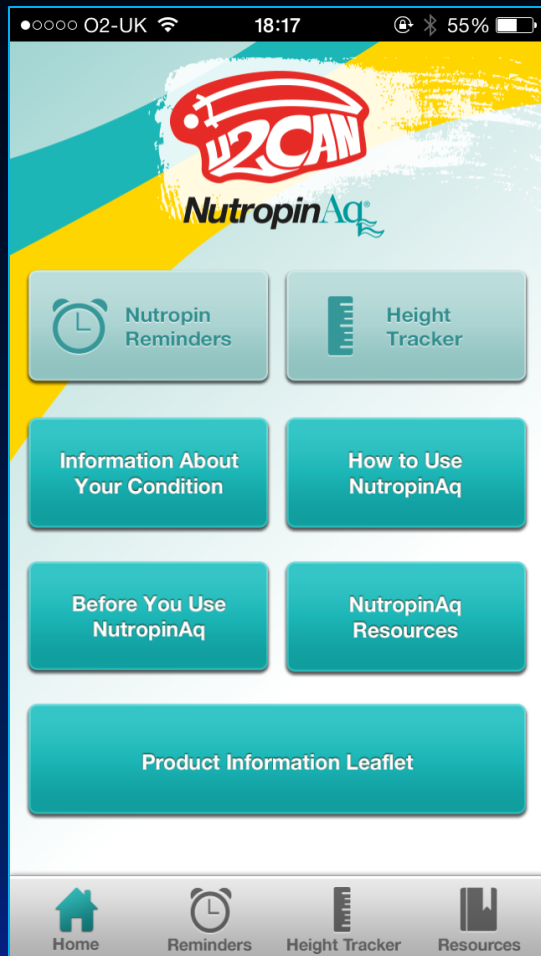


Other incentives – shown at demo?

- Books
- Posters
- Stickers
- Reward charts
- Height charts
- Removable pen covers
- Cool bags

- Bags
- Water bottles
- Fridge magnets
- Phone charms
- Soft toys
- Magazines
- Cameras

Growth Hormone App



Enhanced Nurse Services

- Merck Serono
- Ipsen
- Novo Nordisk

NordiCare® Patient Assessment Tool (nPAT™)

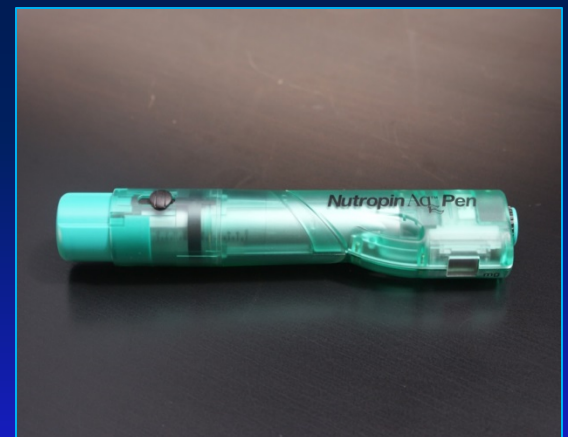
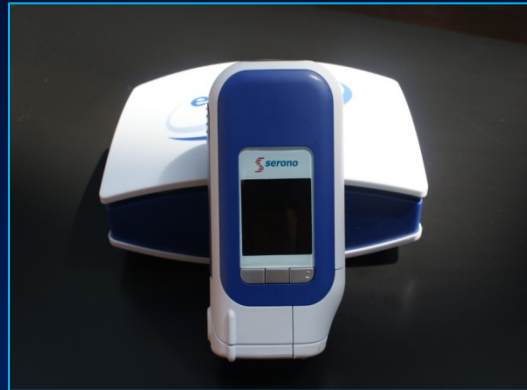
Patient name: _____

Date of birth: _____

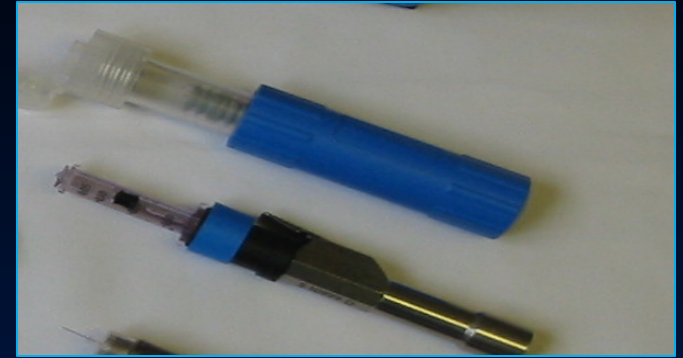
Patient ID number: _____

QUESTIONS	Level of support anticipated		
	Standard	Enhanced	Intensive
How old is the patient?	<2 years <input type="checkbox"/> >18 years <input type="checkbox"/>	11-18 years <input type="checkbox"/>	2-10 years <input type="checkbox"/>
Are there any other health issues which may impact on the use of growth hormone?	No <input type="checkbox"/>	Minor issues that are well-managed <input type="checkbox"/>	Complex healthcare needs <input type="checkbox"/>
Is the patient going on to growth hormone for the first time?	No - on treatment for over a year and has an established routine <input type="checkbox"/>	Is within the first year of treatment <input type="checkbox"/> Confidence growing but advice may be needed with problems <input type="checkbox"/>	Is new to treatment and will require support from outset <input type="checkbox"/>
Are there any language barriers?	None <input type="checkbox"/>	Moderate - some language barriers but understanding can be achieved through relatives and practical demonstration <input type="checkbox"/>	Severe - requires an external translator <input type="checkbox"/>
How does the patient/carer feel about injecting?	Too young to have knowledge <input type="checkbox"/> Carers have no problems <input type="checkbox"/>	Patient uncertain about injecting. Cognitive development may cause fear <input type="checkbox"/>	Patient/carer very apprehensive about injecting. Will need a great deal of support. If needle phobic may need play therapy prior to treatment <input type="checkbox"/>
Will the patient self-inject?	Young patient so carer will inject - no problems perceived <input type="checkbox"/> Patient will inject with good carer support <input type="checkbox"/> Patient fully able to inject <input type="checkbox"/>	Patient wanting to inject themselves - carer apprehension <input type="checkbox"/> Patient prepared to inject but minimal support available to them <input type="checkbox"/>	Patient may have difficulty injecting due to dexterity /sight problems <input type="checkbox"/> Carer may also have problems requiring extra support <input type="checkbox"/>
Will an autoinjection device or hidden needle be helpful?	Not necessarily <input type="checkbox"/>	Useful for patients starting to inject themselves. May benefit from an auto injection device <input type="checkbox"/>	Useful for patients/carers who are apprehensive about injection process/ have dexterity problems <input type="checkbox"/>

GH devices



Needle free devices



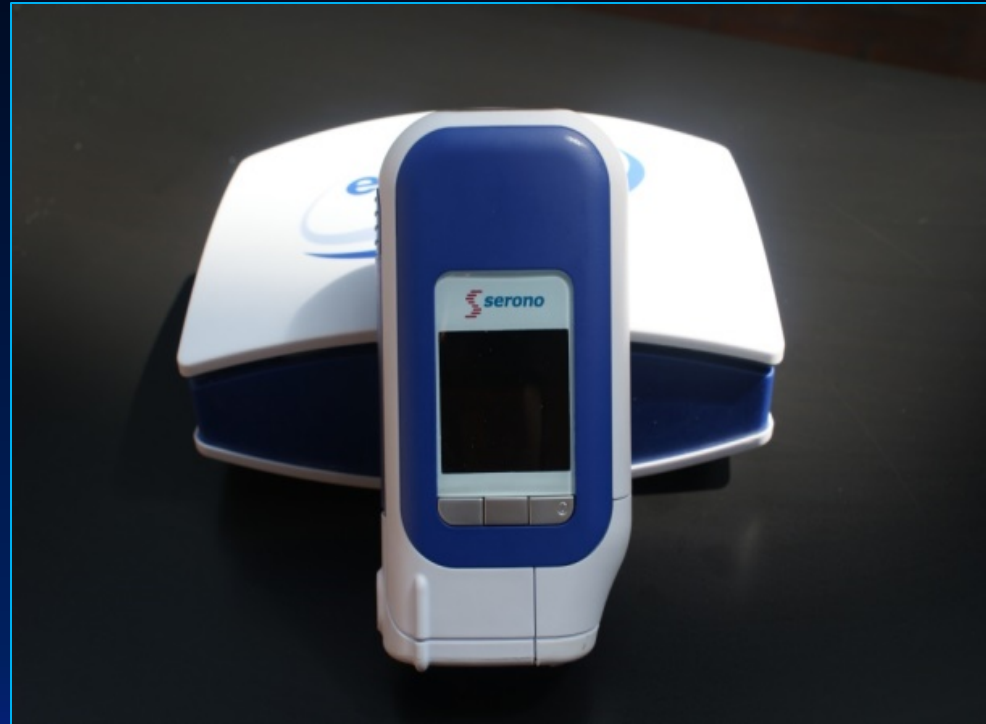
Patient choice – what are the issues?

- Ease of use
- Needle free
- Colour
- Quietness
- Size
- Needle guard
- 'Feel'
- Automatic needle insertion
- Reduced time holding device against the skin post injection

(Wickramasuriya, 2005)

Easypod – Dahlgren 2007

- ‘Very useful’ features:
 - Pre-programmed dose feature
 - Skin sensor
 - On screen instructions
 - Display of remaining dose
 - Confirmation of injected dose
 - Automatic needle attachment



Difference of opinion?



- Various comfort settings
- Dose history
- 'Teach Me' menu
- Multi-lingual instructions
- Refrigeration
- Homecare
- Reconstitution

How well do we know our patients?

- Need to understand parental perceptions and beliefs concerning illness and treatment (*Van Dongen, 2012*)
- Discussions of the patients' view of the disease and their expectations of the treatment (*Haverkamp, 2008*)
 - Shown to increase concordance (*Spoudeas, 2014; Van Dongen, 2012; Cutfield, 2011; Haverkamp, 2008; Kapoor, 2008*)

Nurse / Doctor influence?

- Do we always know what is best for our patients?
- Need a thorough, more detailed understanding
- Nurses in the prime position to know the children and their families more closely
 - Families have our contact details
 - Contact us with queries / concerns
 - Main point of liaison for families

GH licenses held in the UK

Company	GHD	TS	SGA	PWS	CRI	SHOX
Lilly <i>Humatrope</i>	✓	✓	✓	X	✓	✓
Ferring <i>Zomacton</i>	✓	✓	X	X	X	X
Ipsen <i>NutropinAq</i>	✓	✓	X	X	✓	X
Novo – Nordisk <i>Norditropin Simplexx</i>	✓	✓	✓	X	✓	X
Pfizer <i>Genotropin</i>	✓	✓	✓	✓	✓	X
Sandoz <i>Omnitrope</i>	✓	✓	✓	✓	✓	X
Merck – Serono <i>Saizen</i>	✓	✓	✓	X	✓	X

But how does this work in practice?

- Children with learning difficulties
 - Septo Optic Dysplasia
 - Need for quick injection → Zomajet
 - Visual problems → Easypod, digital pen devices
- Teenagers
 - Something small, discreet, disposable → Miniquick
- Girls with Turner syndrome
 - Manual dexterity issues → Easypod, Zomajet
 - Larger doses needed → Easypod, Humatropen (20,24mg)
- Travelling families / children with more than one home
 - Think about non-refrigeration → Miniquick, Norditropin

But how does this work in practice?

- SGA
 - Reduced s/c fat →
 - Want more control over administering the injection
 - No autoinjectors
 - Smallest needle, small vial sizes (4mg, 5mg, 5.3mg)
- Control taken away → Easypod
- Post oncology patients → Zomajet
- Fear of needles
 - Needle free → Zomajet
 - Needle covers → Nutropin Aq, Genotropin pen and Miniquick, Nordipenmate, SurePal

NICE / CCG

- The choice of product should be made on an individual basis after informed discussion between the responsible clinician and parent / carer
- Take into consideration therapeutic need and the likelihood of adherence to treatment
- After the discussion, if more than one is suitable, **the least costly product should be chosen**

££££

How does choice work around the UK?

- Department has limited choice v.
- Free choice of all devices
 - Do we all give patient choice?
 - 89% of 52 centres surveyed do (BSPED audit 2008/2009)
- CNS
 - Chat in clinic
 - Demonstrates all devices
 - Posts out DVDs – follow up phone call
 - Clinic appointment

Informed choice?

Nurses' roles – how to increase concordance

- Initial meeting with children and families (*Smith 1992*)
 - Non judgemental, flexible approach (*Haverkamp, 2008*)
- Spend time with the child and family
 - Get to know their concerns and fears
 - Get the concordance agreement right
- Free patient choice of device (*Kapoor, 2008*)
- Enhanced support
- Education for patients (*Cutfield, 2011*)
 - *Nearing adolescence*
 - *Opinions on their device may change..*

How can we enhance the choice process?

- ? Involve other patients (*Van Dongen, 2012*)
 - GH support days
 - Group demonstration sessions
- ? Courses for children for self-administration
 - Age 10 / 11 (*Van Dongen, 2012*)
- Freedom of choice of all devices (*Spoudeas, 2014; Van Dongen 2012; Kirk, 2010*)
- Explore technology
 - Text messaging
 - Apps

Still remember the child

Conclusion

- Clinical Nurse Specialists in the best position to foster a close relationship with children and their families
- Advanced nursing roles
 - Nurse led clinics
 - Advance patient care with more time
 - Educate the children and families more on their condition, and about GH devices
 - Get to know the families and the implications of their conditions
 - More and more CNSs becoming Independent Prescribers and Advanced Nurse Practitioners

Are we the future...?

Thank you

