

ERT HOMECARE

“The Art of the Possible”



11th INTERNATIONAL MPS
SYMPOSIUM

ADELAIDE

26th JUNE 2010

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Healthcare at Home

Agenda

- Introduction
- UK Overview of High-tech Homecare Services
- UK ERT Homecare
 - Market development
 - Key elements
 - Challenges
 - Results and benefits
- Case studies
- Conclusions



UK – Overview of high-tech homecare services

- ‘Homecare’ is defined as hospital levels of clinical and pharmaceutical care at home or in the community
- In the UK, this is a £1Bn market growing at 15-20% p.a. Both public and private sectors commission and fund homecare
- Strong political drive to care for patients in the community rather than hospital
- Strong political drive for ‘patient choice’ – free to choose location of care
- Most therapy areas are involved: oncology, MS, RA, HIV, EPO and many others
- Healthcare at Home has 100,000 patients on different programmes



UK – Overview of ERT homecare services

- ERT Homecare commenced in 1997 with Ceredase (Gauchers)
- HAH grew ERT services with Cerezyme , then Replagal services
 - homecare part of clinical trials in UK
- Approximately 600 ERT patients currently on homecare in the UK, referred from 8 Centres
 - Cerezyme; Replagal; Fabrazyme; Elaprase; Naglazyme; Aldurazyme; Myozyme; Velaglucerase, Taliglucerase
 - Age ranges 4 – 84; 90% of all patients on homecare programmes
 - Wide range of disease severities are included
 - Variety of race, religion and language catered for
 - Wide range of locations – home, office, school, local health centre
 - Management of infusion pumps – esp. important for paed
- 99% compliance rate
- many patients trained to self-infuse (self or carer) – ‘patient empowerment’



UK ERT HOMECARE – Key Elements

- **Nurse Support:**
 - Requires experienced, fully trained individuals
 - Administration of drug at time and place convenient to patient/family
 - ‘Personalised’ care
- **Pharmacy Support:**
 - Provides specialist pharmaceutical service
 - Dispensing, prescription management, on-call advice to patient, AE monitoring
- **Logistics:**
 - Maintenance of drug at required temperature (2° - 8°C) at all times
 - Delivery to the patient’s home at a mutually agreed time/date
 - Removal of clinical waste
- **Call Centre/Customer Service:**
 - Co-ordination of all service elements
 - Key contact to all involved – patients/families, hospital/clinic, Pharma Cos
 - Reporting outcomes (safety, compliance, costs, PROs, QoL etc)

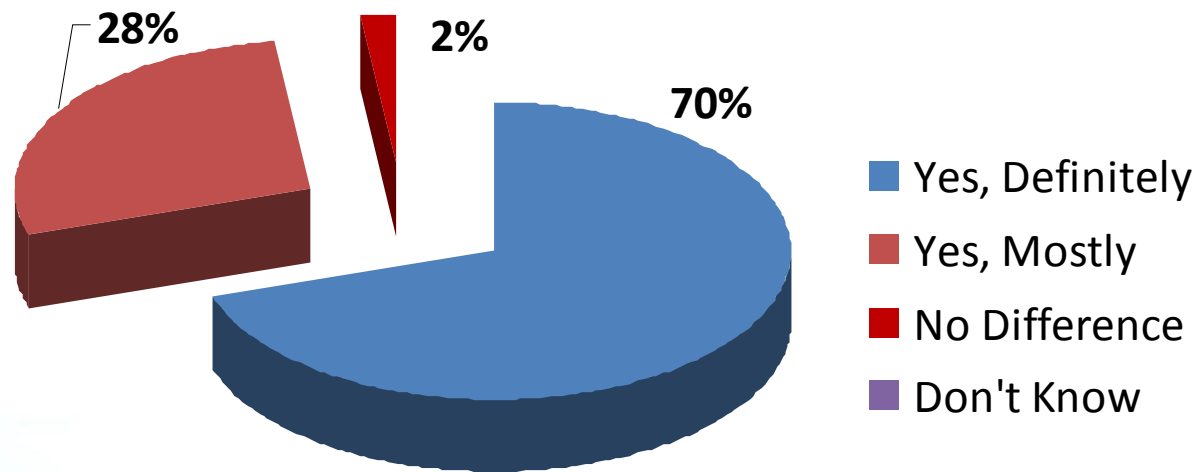


CHALLENGES - Critical Success Factors

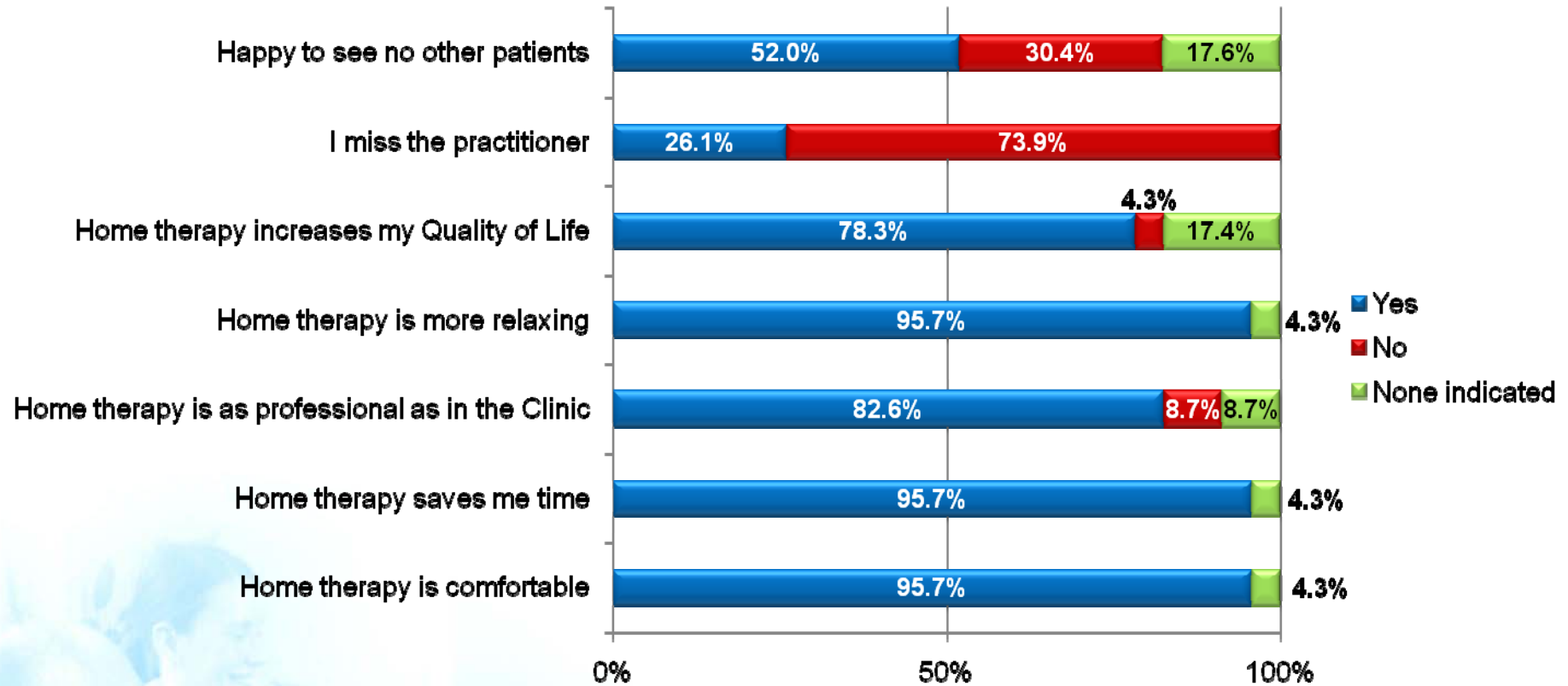
- **Patients/Families:**
 - Patient-centric, holistic care models are critical to success
 - Improving communications (“spreading the word”)
- **Quality services:**
 - Clinical credibility is paramount
 - Management of all stakeholders (many differing expectations)
 - Outcomes measurement and providing evidence of benefits and value
- **Physicians and specialist nurses:**
 - Critical to have clinical champions
 - Belief in homecare benefits and patient choice
- **Payors:**
 - Building proof of cost-effectiveness but this takes time



Has your quality of life improved over the home therapy time ?



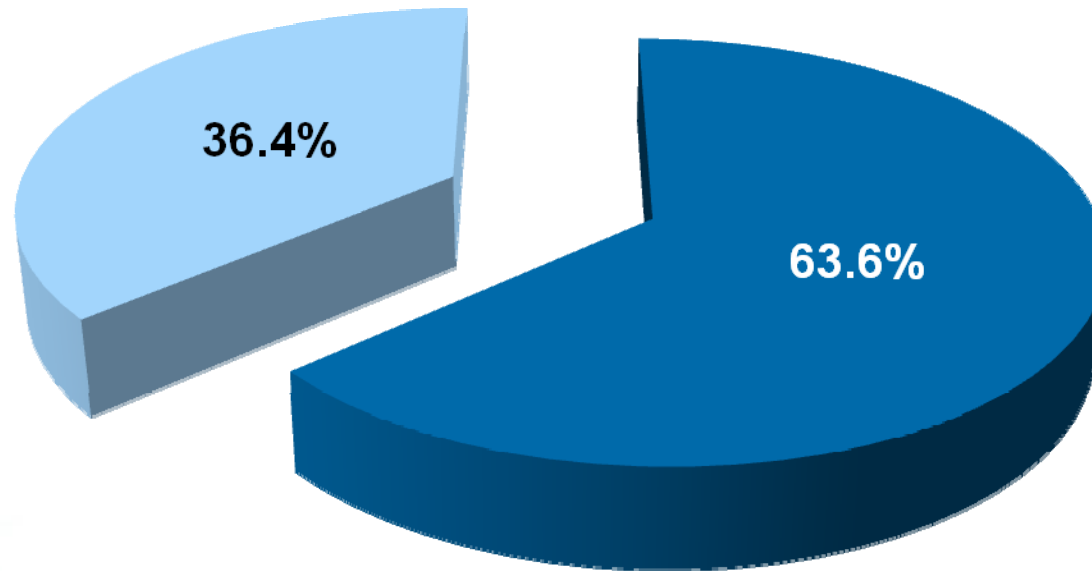
Experience of homecare



Source: HaH Patient Satisfaction Survey, Oct '09

Healthcare at Home

How satisfied are you with homecare compared to infusion in the clinic ?



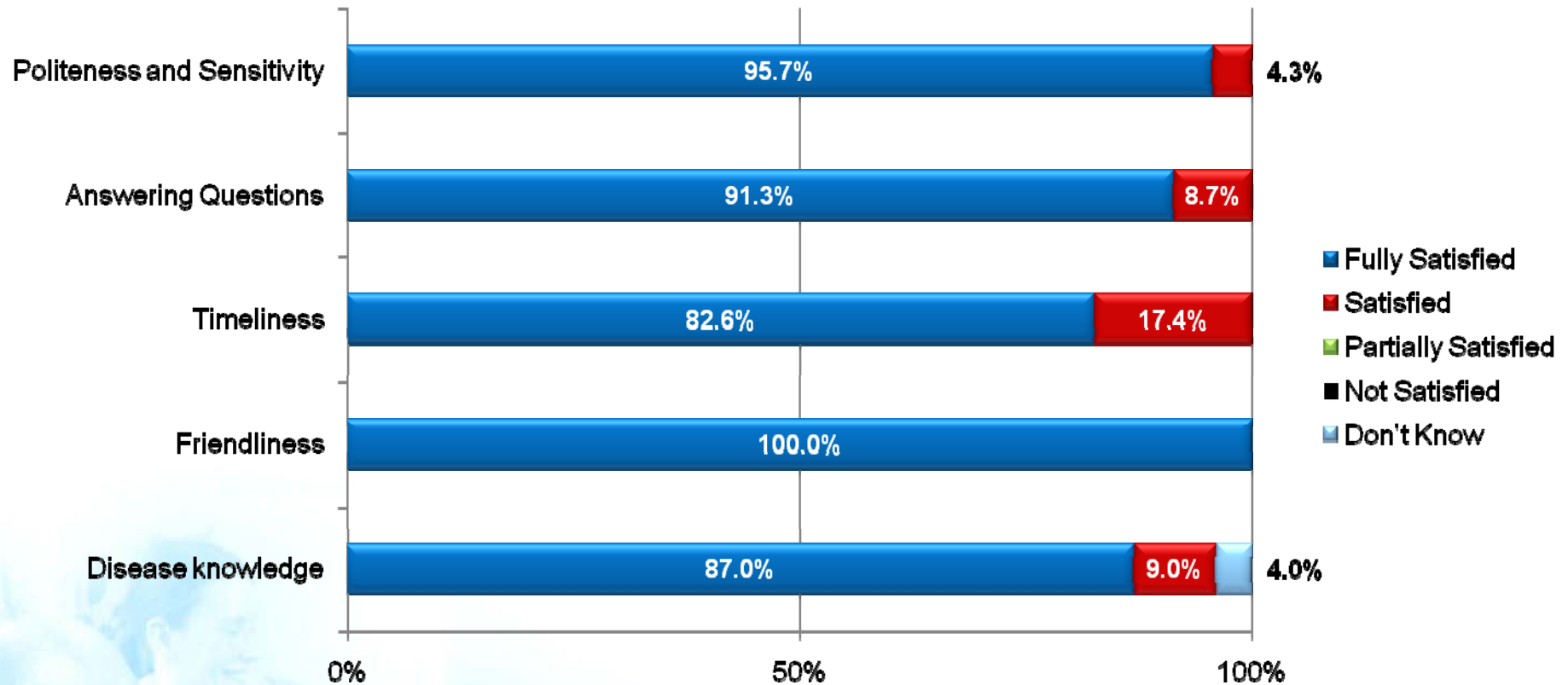
■ More Satisfied ■ Equally Satisfied
■ Less Satisfied ■ Don't Know



Source: HaH Patient Satisfaction Survey, Oct '09

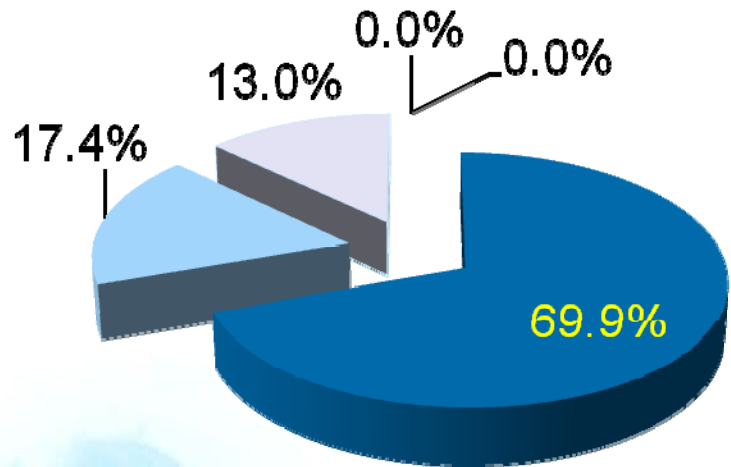
Healthcare at Home

Satisfaction with nurse service



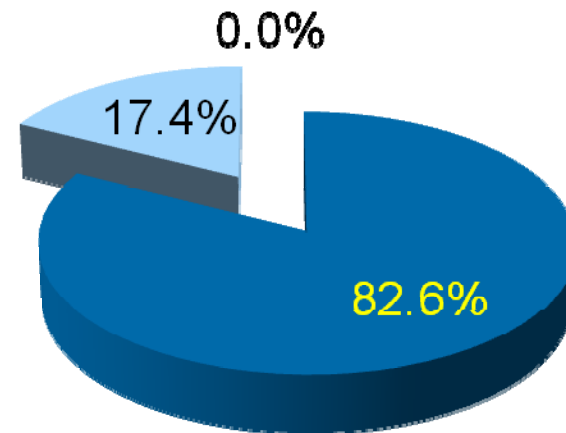
Healthcare at Home Service

How would you rate the quality of the HaH service?



■ Very Good ■ Good ■ Medium
■ Poor ■ Not stated

Would you recommend the HaH service ?



■ Yes ■ Maybe ■ No



Source: HaH Patient Satisfaction Survey, Oct '09

Healthcare at Home

UK ERT HOMECARE

CASE STUDIES



Healthcare at Home

Case Study 1 – ‘Alan’

- 35-year old Fabry patient
- Had homecare treatment for ~10 years
- Keen to maintain job and working life
 - therefore infusions at home in evenings
- Developed confidence and opted for self-care training programme
 - Specific programme over several home visits
 - HAH nurse assesses competence to self-infuse and reports to Physician
- Patient now in complete control over own treatment
 - HAH nurse continues to monitor and support if/when required



Case Study 2 – ‘Billy’

- 10-year old MPS VI
- Ambulatory pump used for infusion → mobility and some independence
- Important for Billy and family that schooling is maintained
- Therefore, nurse attends school on infusion days:
 - Close liaison with school
 - During infusion, close observation of Billy at all times (nurse sits at back of class or uses separate room with homework)
- Holidays: family keen to go away to their caravan in the Lake District
 - Nurse meets Billy and family at caravan on treatment days
 - Drug and ancillaries all transported by nurse (cold-chain maintained at all times)
 - Ensures no missed infusions
- Nurse is genuine ‘friend of family’



CONCLUSIONS

- Homecare is in growing demand across all geographies
- ERT has been the leading light in the development of ‘high-tech’ homecare for the past 12 years
 - Patient/family-centric care
 - Best practice and key physician support
 - Patient/family empowerment
- Significant pride in everyone’s achievements
- Providing evidence (safety, outcomes, cost) is critical
- Further development, improvements and geographical expansion of the homecare model are possible with all stakeholders’ help



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THANK YOU!



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