

# A National Programme for Intestinal Failure

## *Bridging the North South Divide*

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# Talk Outline

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- Intestinal failure (IF) – patients perspective
- Current intestinal failure care pathway in Republic of Ireland
- Proposed national intestinal failure service configuration

# Intestinal Failure Patients

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## Type II Intestinal Failure



## Type III Intestinal Failure



# IF Service Requirement Republic of Ireland

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## Type II Intestinal Failure

Prevalence 18 – 20 patients per million of population annually

ROI population – 4.7 million

80 – 100 Type II IF patients per annum

## Type III Intestinal Failure

Prevalence 15 – 20 patients per million of population annually

ROI population – 4.7 million

70 – 94 Type III IF patients per annum

*\*10 – 30 new HPN cases per year*

# Intestinal Failure in ROI – Audit Data 2016

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- Audit conducted between April 2015 - March 2016
- Data returned by 30 ROI acute hospitals
- 67 patients identified meeting criteria for IF receiving PN
- Care distributed across 16 hospitals
- The median number of patients treated in each centre was 2.5 (range: 1-17)

# Paediatric IF Service – OLHSC, Dublin

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- Paediatric IF unit established for 17 years
- Prof. Billy Bourke, lead consultant
- Clinical nurse specialists
- Senior dietitian
- Senior pharmacist
- Social work / Psychology
- Administrative / audit support

# Unstructured Intestinal Failure Service in ROI

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- No specialist service for adult IF patients
- Patients with highly complex needs arising from IF are dispersed across a large number of acute hospitals
- No ROI acute hospital meet minimum NHS commissioning standards for secondary level IF centres
- In NI, Belfast City Hospital operates a **12 bedded IF unit** for a population of 1.6 million

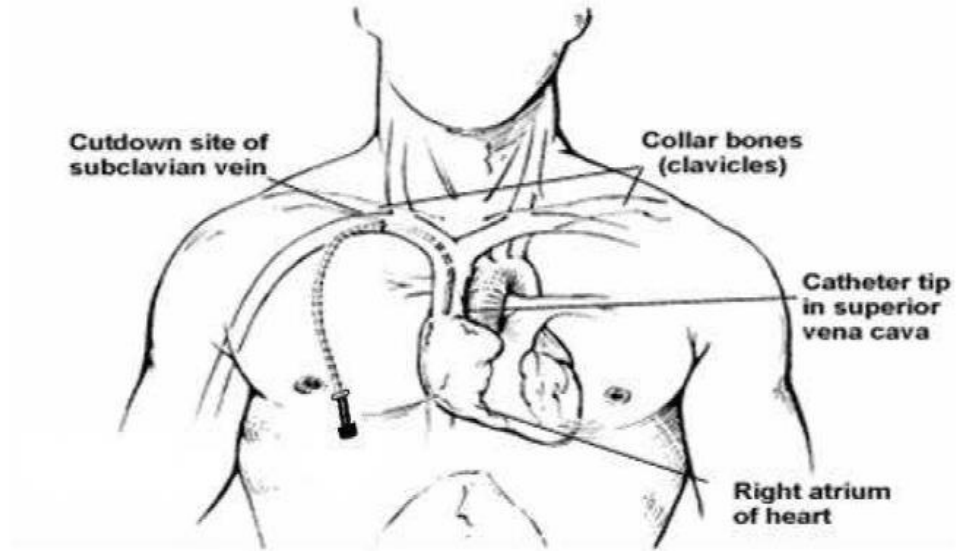
# Republic of Ireland HPN Underutilisation

## Prevalence of HPN use in European countries

| Country             | Population (m) | 2010 period prevalence per million population | Point prevalence (31 Dec 2010) per million population | National specialist centres |
|---------------------|----------------|---|---|-----------------------------|
| Denmark             | 5.3            | 66  | 47  | Yes (3)                     |
| Republic of Ireland | 4.4            | 10.1  | 7.5   | No                          |
| England             | 52             | unknown                                       | 19.3*   | Yes (2)                     |
| Germany             | 82             | unknown                                       | 49  | Yes ('few')                 |
| Netherlands         | 17             | 14.7  | unknown   | Yes (2)                     |
| N. Ireland          | 1.8            | 15.6  | 15.6  | Yes (1)                     |
| Scotland            | 5.2            | 23  | 17.5*   | Yes (11 – network model)    |
| Wales               | 3.0            | unknown                                       | 20*   | Yes (3)                     |



# Complications of Home Parenteral Nutrition



## HPN complication rates ROI audit:

-Average emergency admissions in study period - 2.86

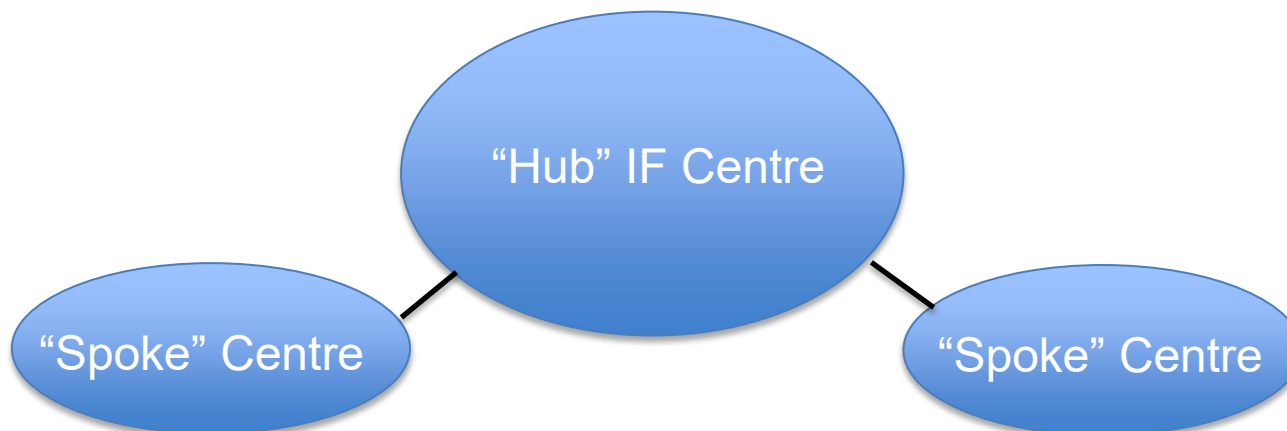
## Standard international HPN complication rates:

1 - 2 complications per 1000 days.

# Infrastructure for National IF Service

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- **IF service managing 100% of the national requirement:**
  - Manage 90 type II IF patients per year
  - Capacity to manage at least 70 HPN patients
  - Capacity to train at least 10 new patients per annum
  - 16 dedicated inpatient beds
  - Well resourced multidisciplinary team
  - Step down facilities in 1 – 2 acute hospitals



# Configuration of St James's Hospital IF Unit

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- SJH IF unit **would serve 50% of the national IF demand**
- **SJH unit would be established as 8 bed inpatient unit:**
  - Manage caseload of 50 inpatients per year
- **Specialised outpatient service for type III IF patients**
  - 100% of OLHSC transfers at age 18 years
  - Community patients attending low volume centres
  - 50% of national HPN cohort **within 1<sup>st</sup> year**

# Progress

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- Business case prepared
- Presented to HSE August 2016
- Advocacy efforts underway

# Summary

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- Type II and III IF patients require specialist management
- In the ROI the care of this patient group is dispersed across a large number of non-specialist acute hospitals
- Audit data demonstrates suboptimal patient outcomes in ROI compared with other developed health care systems

# Conclusions

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- A national IF centre for adults is urgently required
- No adult service for graduating paediatric IF patients
- Inequity of access to specialist care on the island of Ireland
- Unprecedented in a developed economy to be without adult IF / HPN programme