



International Conference

optimal
nutritional care
for all

MALNUTRITION: FROM AWARENESS TOWARDS CONTROL

A NUTRITIONAL CARE POLICY SUMMIT

Turin 6 & 7 June 2024



Navigating Nutritional Policies in the UK: Valuable Lessons from Intestinal Failure Strategies



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Disclosures

- Simon Lal has received honoraria and/or educational support from Takeda, Zealand, VectivBio, Fresenius Kabi, B Braun, Baxter, Northsea.
- Simon Lal's department has received investigator-initiated/unrestricted research grants from Fresenius Kabi, Baxter and Takeda.

INTESTINAL FAILURE

What is the problem?

What is the U.K. experience?

What can we do?



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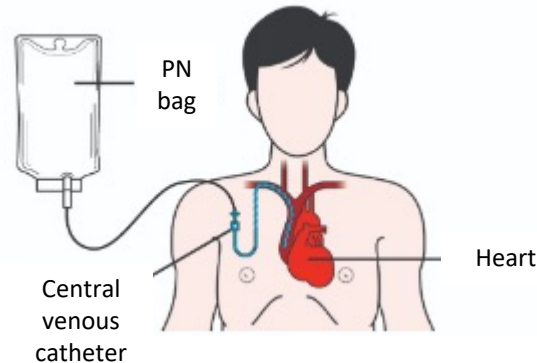


INTESTINAL FAILURE: DEFINITION

Intestinal failure is defined as the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation (Parenteral Nutrition or PN) is required to maintain health and/or growth.

...the patient needs intravenous feeding to survive (known as 'Parenteral Nutrition (PN)')

...administered via a central venous catheter.



...can be temporary or lifelong → home PN (HPN).

...but is associated with risk (e.g. catheter infections or thrombosis) → patient's 'lifeline'!

Prevalence of Home Parenteral Nutrition (Chronic IF)

Country	Prevalence (per million)
Brazil	0.25
Spain	6
Argentina	6.75
Australia & New Zealand	9.4
Canada	14
U.K.	50
U.S.A.	79
Denmark	80

The prevalence is still ZERO in too many countries worldwide: the forgotten organ failure!



Shared with patient permission

42 + years on Home Parenteral Nutrition Wife, mother and grandmother



The most important thing to me is my family and once on HPN in 1982. I felt part of family life again.

I have self-managed my parenteral nutrition for all this time and have only had 3 catheter infections in 42 years.

I go on regular walks....I also go on holiday and have been on many cruises.



www.atlasif.eu

Intestinal Failure care not available in her country Transferred > 1000miles for treatment in 2017



Unable to access home parenteral nutrition in Romania in 2017, she made the decision to permanently move to France, living apart from family and friends.

For me, it is obvious that I am not returning to Romania for good.

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U.K. INTESTINAL FAILURE SPECIALIST CARE

In April 1996, the Department of Health designated two National Centres for the management of severe (needing HPN) Intestinal Failure, recognising the benefits of centralised care.



SALFORD ROYAL



ST MARK'S, LONDON

PICTURES TO BE ADDED

Optimising the care of patients with severe IF for Home PN

Complex GI problems
Multidisciplinary care
Prolonged hospital admissions
Home PN
*Surgery after recuperation may or
may not allow HPN cessation*

**BEST OUTCOMES:
SPECIALISED INTESTINAL FAILURE UNITS**

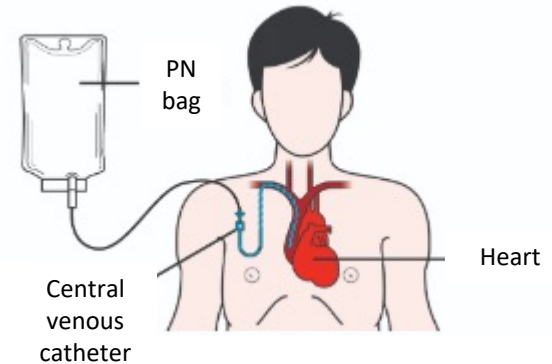
HEALING WITHOUT SURGERY

Anonymised

Intravenous supplementation type and volume are associated with 1-year outcome and major complications in patients with chronic intestinal failure

Loris Pironi ¹,²,³,⁴,⁵,⁶,⁷,⁸,⁹,¹⁰,¹¹,¹²,¹³,¹⁴,¹⁵,¹⁶,¹⁷,¹⁸,¹⁹,²⁰,²¹,²²,²³,²⁴,²⁵,²⁶,²⁷,²⁸,²⁹,³⁰,³¹,³²,³³,³⁴,³⁵,³⁶,³⁷,³⁸,³⁹,⁴⁰,⁴¹,⁴²,⁴³,⁴⁴,⁴⁵,⁴⁶,⁴⁷,⁴⁸,⁴⁹,⁵⁰,⁵¹,⁵²
 Ezra Steiger,² Francisca Joly,³ Geert J A Wanten,⁴ Cecile Chambrier,⁵ Umberto Aimasso,⁶ Anna Simona Sasdelli,¹ Kinga Szczepanek,⁷ Amelia Jukes,⁸ Miriam Theilla,⁹ Marek Kunecki,¹⁰ Joanne Daniels,¹¹ Mireille J Serlie,¹² Sheldon C Cooper,¹³ Florian Poullenot,¹⁴ Henrik Højgaard Rasmussen,¹⁵ Charlene W Compher,¹⁶ Adriana Crivelli,¹⁷ Sarah-Jane Hughes,¹⁸ Lidia Santarpia,¹⁹ Francesco William Guglielmi,²⁰ Nada Rotovnik Kozjek,²¹ Lars Ellegard,²² Stéphane M Schneider,²³ Przemysław Matras,²⁴ Alastair Forbes,²⁵ Nicola Wyer,²⁶ Anna Zmarzly,²⁷ Marina Taus,²⁸ Margie O'Callaghan,²⁹ Emma Osland,³⁰ Ronan Thibault,³¹ Cristina Cuerda,³² Lynn Jones,³³ Brooke Chapman,³⁴ Peter Sahin,³⁵ Núria M Virgili,³⁶ Andre Dong Won Lee,³⁷ Paolo Orlandoni,³⁸ Konrad Matysiak,³⁹ Simona Di Caro,⁴⁰ Maryana Doitchinova-Simeonova,⁴¹ Luisa Masconale,⁴² Corrado Spaggiari,⁴³ Carmen Garde,⁴⁴ Aurora E Serralde-Zúñiga,⁴⁵ Gabriel Oliveira,⁴⁶ Zeljko Krznaric,⁴⁷ Estrella Petrina Jáuregui,⁴⁸ Ana Zugasti Murillo,⁴⁹ José P Suárez-Llanos,⁵⁰ Elena Nardi,¹ André Van Gossum,⁵¹ Simon Lal⁵²

2194 HPN patients
51 centres
22 countries



*Mortality & catheter complication rates (thrombosis & infections) are associated with IF centre size (and experience)
→ supporting specialised & centralised care*

Salford IF Service, est^d. 1979



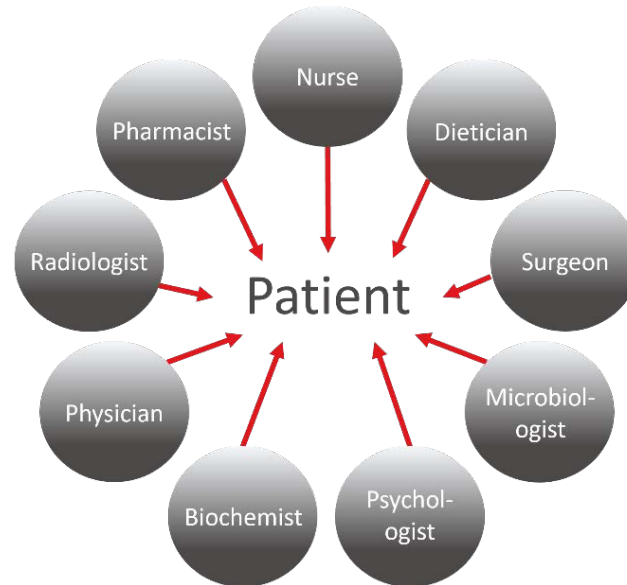
4 beds (1979)



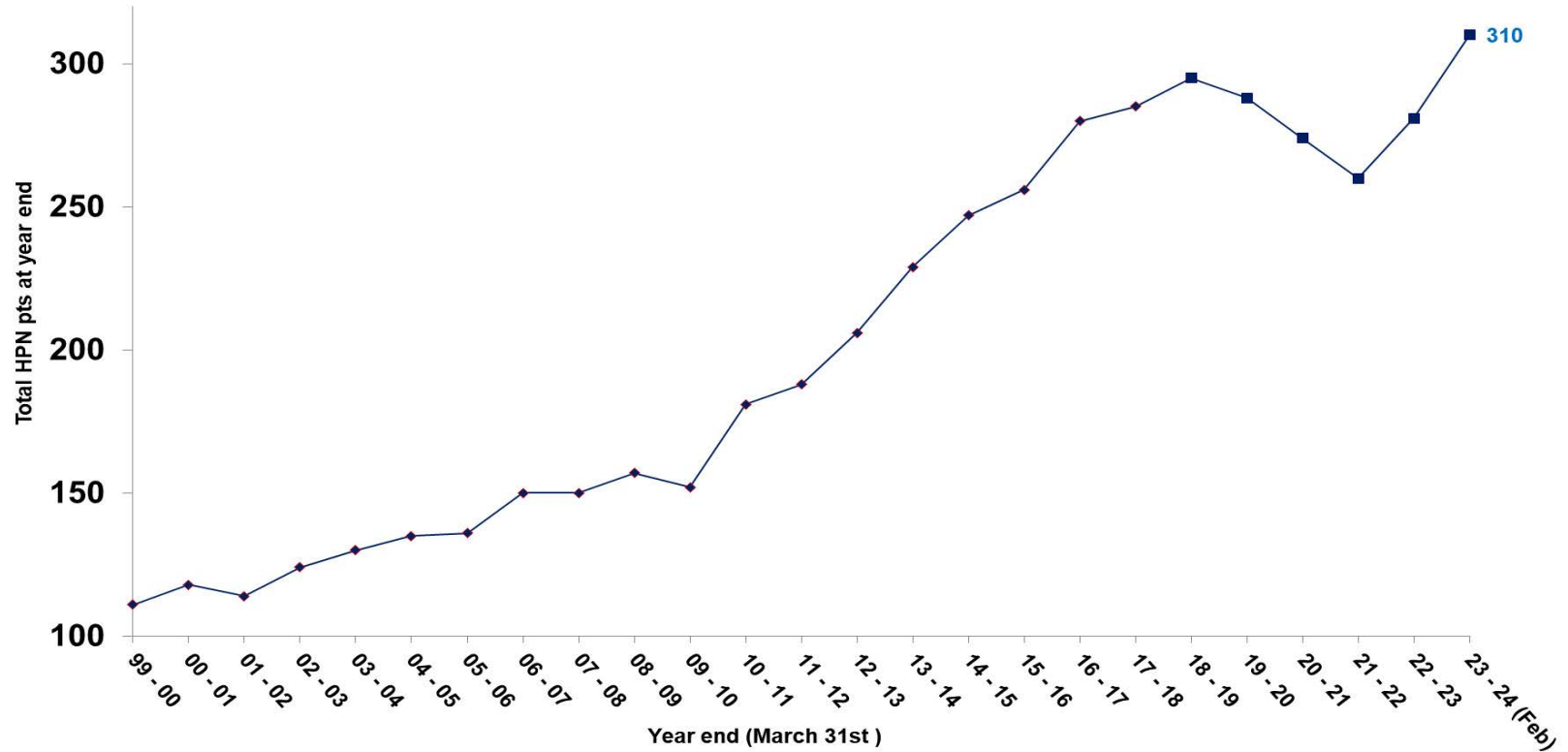
13 beds (1996)



21 beds (2011)



Increasing HPN patients at Salford IFU



IF Services in England 2021 onwards

- More centres needed in other regions because of increasing patient numbers.
- NHS-England policymakers & clinicians: procurement process based on IF service specifications.



IF Services in England 2021 onwards

- Development of more specialised IF centres.
- **2 National reference centres**
 - Multi-disciplinary mentoring
 - Complex case discussions
 - Shared Policies & Protocols
 - Data
 - Quality Improvement
- ➔ *benchmark & improve quality standards in new centres.*



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Quality-of-Care Standards in Adult Type 3 Intestinal Failure caused by benign disease: European Society of Clinical Nutrition and Metabolism (ESPEN) Position Paper.

Lal S et al. *In Draft (Delphi round completed February 2024)*

Structure

- Referral criteria.
- Multi-disciplinary team staffing, experience & education.
- Clinical services, facilities & networks.

Process

- Waiting list management
- In-patient care, optimisation & Home PN commencement.
- Outpatient & emergency care, with local hospital networking.

Outcomes

- Service delivery (e.g. waiting times, length of stay, readmission rates)
- IF & Home PN-related complications: morbidity and mortality.
- Quality of life: patients & families.

→ IF Registries

ATLAS programme launch: European Parliament 2018

- To raise awareness and address variability of access to specialist chronic (type 3) IF care between countries – *as identified by the varied HPN prevalence rates.*
- Clinicians, patients & policymakers.



Improving standards of care in Chronic Intestinal Failure

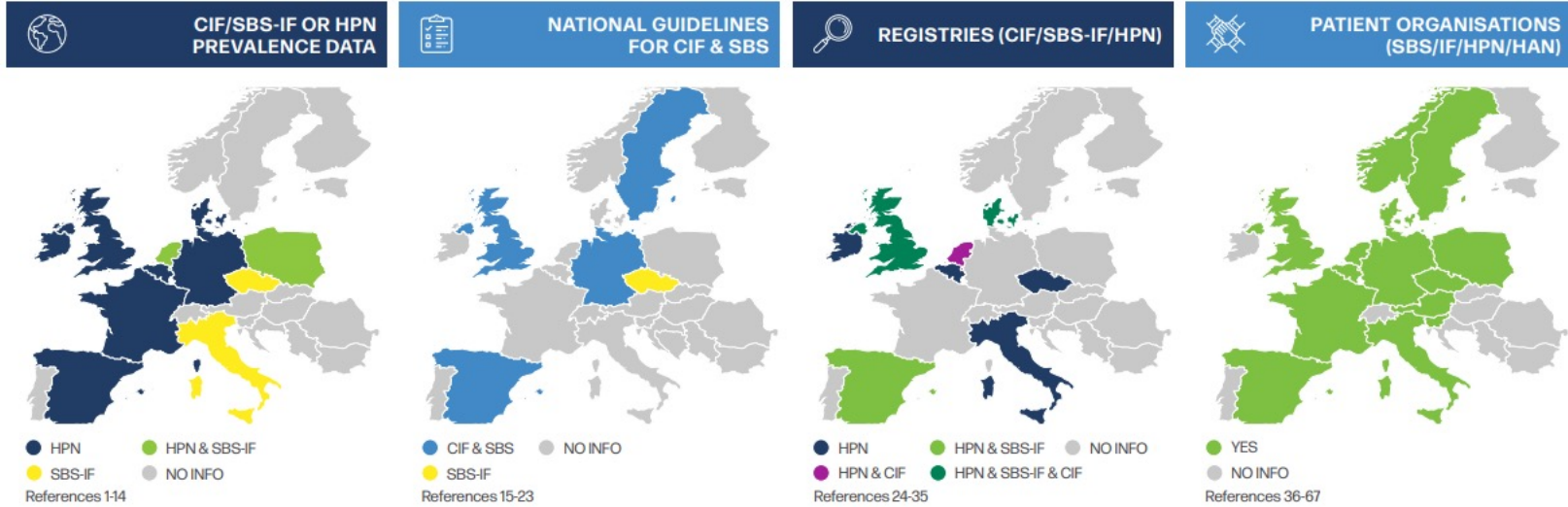
Written by **Brian Johnson** on 20 April 2018 in **Event Coverage**

Much more needs to be done to reduce inequalities of care for people suffering from Chronic IF, a rare disease and organ failure, MEPs have been told.

THE PARLIAMENT 
POLITICS, POLICY AND PEOPLE **MAGAZINE**

www.ATLASIF.eu

THE INTESTINAL FAILURE LANDSCAPE IN EUROPE



ATLAS FINDINGS

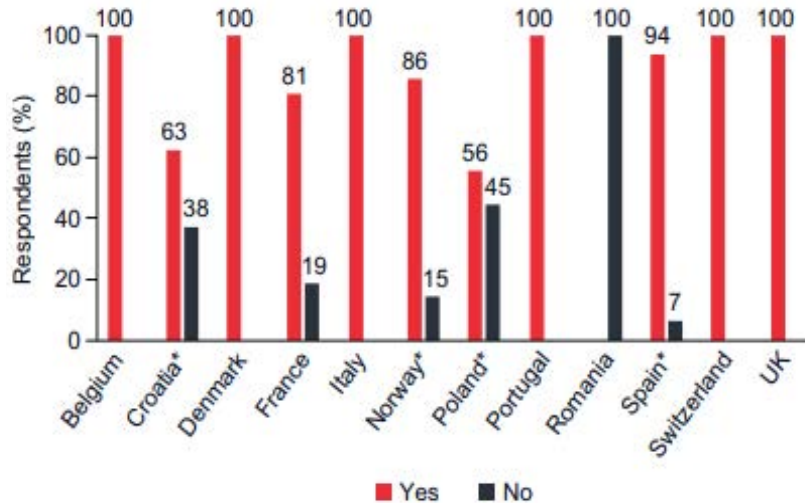
- There is a lack of clear epidemiological data. This makes it difficult for countries to know the true size of the population affected by IF and allocate the resources required to treat IF.
- Currently, some countries have no implemented national guidelines for IF care. This could be a contributing factor to variable standards of care across Europe.
- 16 European countries have no available evidence of patient registries relating to IF, making it hard to collect and share data about the IF patient care pathway.
- There is a need for more IF-specific patient groups at a national level, and European and international collaboration between those groups, to raise the IF patient voice.

Please see the following pages for references.

Survey of healthcare professionals' experiences of care delivery in patients with chronic intestinal failure: ATLAS of Variance

Parnia Geransar ^a, Simon Lal ^b, Palle B. Jeppesen ^c, Loris Pironi ^{d, e}, Ewelina Rzepa ^f, Stéphane M. Schneider ^{g, *}

Is HPN available?



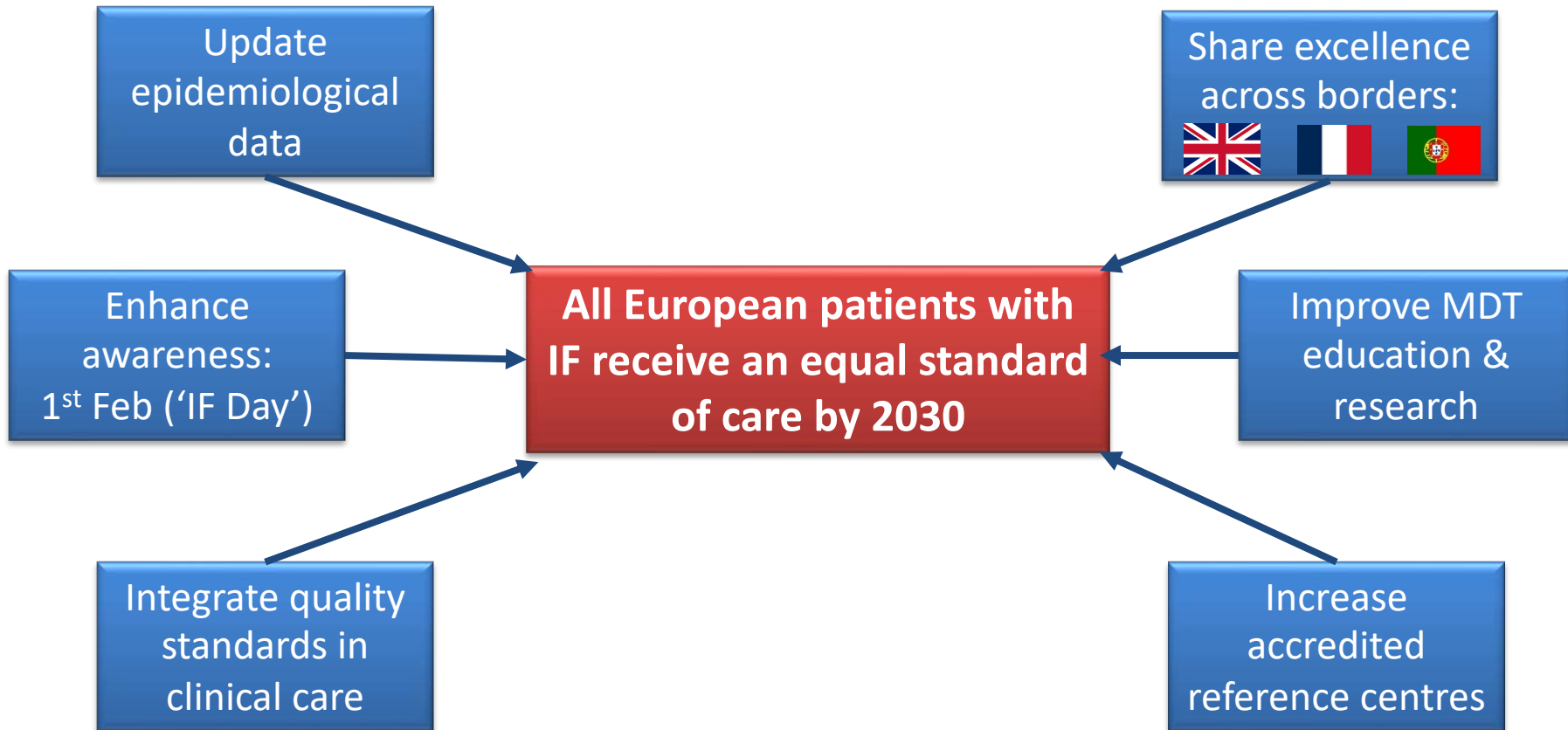
- 13% of 119 health care professionals reported HPN wasn't available.
- Most important reported unmet needs included lack of:
 - disease awareness among non-specialists;
 - accredited referral centres;
 - funding
- Transplantation available in 54% respondents' countries.

➔ **Further work in Europe [ONCA]**

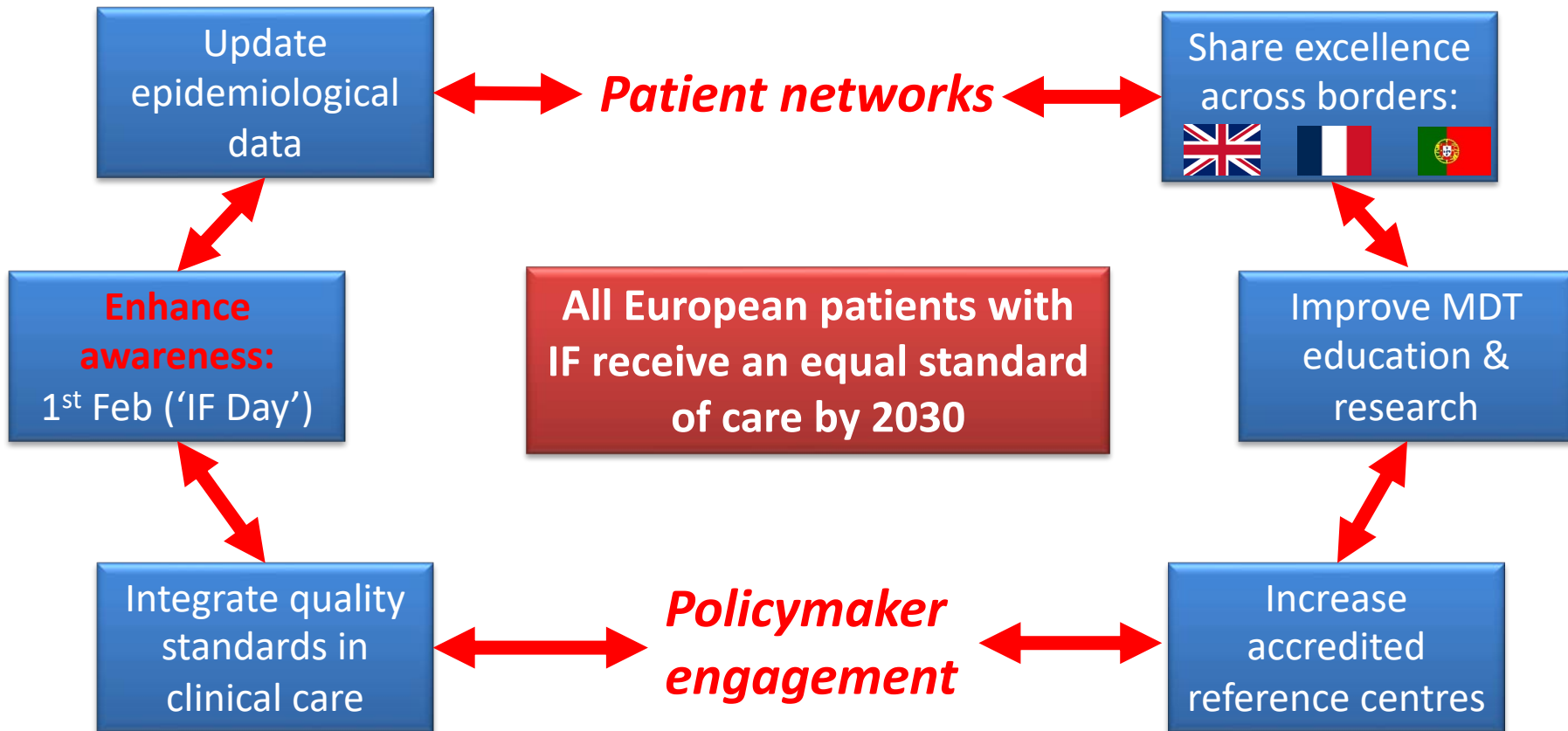
Building on the ATLAS Programme

**All European patients with
IF receive an equal standard
of care by 2030**

Building on the ATLAS Programme



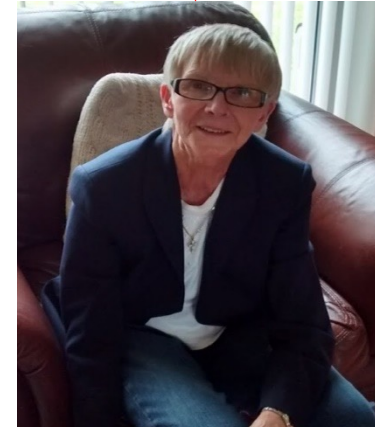
Building on the ATLAS Programme



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LEAVE NO
ONE BEHIND



Thank-you...Questions?

