

TAKEDA ATLAS DASHBOARDS

Introduction

ATLAS is an European stakeholder collaboration founded in 2016 and is initiated and funded by Takeda. ATLAS was formed as a policy change programme aiming to show the disparity of care for intestinal failure (IF) patients, and to work towards ensuring that all IF patients in Europe receive an equal standard of care. ATLAS is guided by a Steering Committee made up of clinicians and representatives from patient organisations to develop and enact solutions to the unmet need and treatment requirements of people with IF. The ATLAS Country Dashboards aim to create a standardised benchmark platform from which to measure, monitor and communicate about the IF treatment and care landscape.

Methodology

Search methods and sources: Data collection and validation took place from October 2019 to April 2020 (except the search for clinical trials data, which was performed in August 2020). Sources are provided as references and include peer-reviewed academic sources, official Governmental or national/regional authority sources, and reputable online sources that are publicly accessible.

Some of the data points may change over time in the original public source (for example, population), and therefore an audit trail is available on request providing evidence of the data point value at the time of access.

Clinical trials ('research') search methodology: Source: <<https://clinicaltrials.gov/>>, condition or disease: "renal insufficiency", "liver failure", "short bowel syndrome & intestinal failure", study type: "all studies", study results: "all studies", locations: "Europe", time frame: "study start from 12/08/2010 to 12/08/2020", status - recruitment: "recruiting", "enrolling by invitation", "active", not recruiting" and "completed", sex: "all", study type: "all".

No information available (NO-INFO): For some data points, no information was available at the time the search was performed (October 2019 to April 2020 for all data points, except for search for clinical trials data, which was performed in August 2020).

Translation from non-English sources: Sources not available in English have been translated. These datapoints/references are indicated by a † in the Dashboards.

Validation, quality control (QC) and approval: The data presented in the Dashboards have undergone a series of validation, QC, and approval processes according to Takeda Standard Operating Procedures and are correct at the time of approval/publication.

Disclaimers

Intended for a global audience (outside of the US/UK).

This project is initiated and funded by Takeda.





OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN AUSTRIA



COUNTRY CONTEXT	
Population ¹	8,751,815
Health expenditure (US\$ billion) ^{2†}	43.1
% government health expenditure ³	72.39%
% out-of-pocket expenditure ⁴	19.20%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	9,748/100,000
Chronic liver disease prevalence (rate) ⁵	14,145/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials - Liver failure ⁶	7
# clinical trials (from 12/08/2010 to 12/08/2020)**	48
# clinical trials - Renal failure ⁷	48
# clinical trials - Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Die Chronischen Experten ^{10†}	SBS
ÖMCCV ^{11†}	IBD, SBS

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹²	<input checked="" type="checkbox"/> YES
Is HPN reimbursed in the country? ¹²	<input checked="" type="checkbox"/> YES

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN BULGARIA



COUNTRY CONTEXT	
Population ¹	7,036,852
Health expenditure (US\$ billion) ²	4.30
% government health expenditure ³	51.86%
% out-of-pocket expenditure ⁴	46.55%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	13,915/100,000
Chronic liver disease prevalence (rate) ⁵	18,217/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	
- Liver failure ⁶	2
- Renal failure ⁷	32
- Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
NPO ^{10†}	General, not SBS-IF/CIF specific

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹¹	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN BELGIUM



COUNTRY CONTEXT	
Population ¹	11,498,527
Health expenditure (US\$ billion) ^{2,3†}	34.763
% government health expenditure ⁴	77.22%
% out-of-pocket expenditure ⁵	17.64%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*6}	HPN adult prevalence: 14 /million/year (59.6% HPN due to SBS)
Chronic kidney disease prevalence (rate) ⁷	9,735/100,000
Chronic liver disease prevalence (rate) ⁷	12,856/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country? ⁶	YES

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁶	6

RESEARCH	
# clinical trials - Liver failure ⁸	12
# clinical trials - Renal failure ⁹	73
# clinical trials (from 12/08/2010 to 12/08/2020)**	
# clinical trials - Intestinal failure ¹⁰ and short bowel syndrome ¹¹	5

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Hello TPN ^{12†}	SBS
La vie par un Fil Belgique asbl ^{13†}	SBS

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁴	YES
Is HPN reimbursed in the country? ¹⁵	YES

NATIONAL GUIDELINES	
National guidelines: CIF ¹⁶	No Belgian guidelines, ESPEN guidelines are used
National guidelines: SBS ¹⁶	No Belgian guidelines, ESPEN guidelines are used

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

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References: 1. The Global Cancer Observatory (2018), Belgium, World Health Organization, viewed 21 August 2020, <http://gco.iarc.fr/today/data/factsheets/populations/56-belgium-fact-sheets.pdf>. 2. Institut national d'assurance maladie-invalidité (INAMI) (2019), Le budget 2020 de l'assurance soins de santé est approuvé, Institut national d'assurance maladie-invalidité (INAMI), viewed 21 August 2020, <https://www.inami.fgov.be/fr/nouvelles/Pages/budget-soins-sante-20191122.aspx>. 3. Institut national d'assurance maladie-invalidité (INAMI) (2019), ANNEXE 1 : Aperçu du budget - Soins de santé, Institut national d'assurance maladie-invalidité (INAMI), viewed 21 August 2020, <https://www.inami.fgov.be/SiteCollectionDocuments/aperçu_budget_2020.pdf>. 4. The World Bank, Domestic general government health expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 5. The World Bank, Out-of-pocket expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 6. UMBRAIN, N. et al. (2019), Impact of nutrition support team (NST) funding from the Belgian National Health Insurance (NHI) on the quality of care of home parenteral nutrition (HPN) in adults with benign diseases. Clinical Nutrition. 38, S59-S296. 7. Institute for Health Metrics and Evaluation (IHME) (2017), GBD Compare | Viz Hub, Global Health Data Exchange, viewed 21 August 2020, <https://vizhub.healthdata.org/gbd-compare/?fbclid=IwAR2wKFTCSeYbak fuufJbahlarjUmejYfdHtVS9dhKcTgNDU-SM4TJRJuf0>. 8. US National Library of Medicine, Clinical Trials.gov, Liver Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1232&map.y=392&recrs=adef&cond=Liver+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 9. US National Library of Medicine, Clinical Trials.gov, Renal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=1715>. 10. US National Library of Medicine, Clinical Trials.gov, Intestinal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1209&map.y=382&recrs=adef&cond=intestinal+failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 11. US National Library of Medicine, Clinical Trials.gov, Short Bowel Syndrome, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1199&map.y=387&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 12. Hello TPN. 2019. Homepage. Viewed 21 August 2020, <https://www.vzwhellotpn.be>. 13. La Vie par un Fil. 2020. Homepage. Viewed 21 August 2020, <http://www.lavieparunfilbelgique.be/index.php>. 14. PIRONI, L. et al. (2020), Home parenteral nutrition provision modalities for chronic intestinal failure in adult patients: An international survey. Clinical Nutrition. 39(2), 585-591. 15. MISTIAEN, P. et al. (2019), Organization and reimbursement of enteral and parenteral nutrition in and outside of the hospital in Belgium. Belgian Healthcare Knowledge Centre (KCE), Report 315. 16. BAXTER, JP. et al. (2012), Home parenteral nutrition: An international benchmarking exercise. Clinical Nutrition. 7(5), E211-214. † Indicated data found in non-English language sources. Information has been translated for inclusion.



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN CROATIA



COUNTRY CONTEXT	
Population ¹	4,164,772
Health expenditure (US\$ billion) ²	4.142
% government health expenditure ³	82.83%
% out-of-pocket expenditure ⁴	10.97%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	13,163/100,000
Chronic liver disease prevalence (rate) ⁵	17,654/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{6†}	1

RESEARCH	
# clinical trials - Liver failure ⁷	0
# clinical trials - Renal failure ⁸	13
# clinical trials - Intestinal failure ⁹ and short bowel syndrome ¹⁰	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
HUCUK ^{11†} , Colonos ^{12†}	IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹³	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ^{14†}	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

References: 1. The Global Cancer Observatory (2018), Croatia, World Health Organization, viewed 21 August 2020, <http://gco.iarc.fr/today/data/factsheets/populations/191-croatia-fact-sheets.pdf>. 2. Calculated by using the GDP (current US\$ billion) and the healthcare % share of GDP. 3. The World Bank, Domestic general government health expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 4. The World Bank, Out-of-pocket expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 5. Institute for Health Metrics and Evaluation (IHME) 2017, GBD Compare | Viz Hub, Global Health Data Exchange, viewed 21 August 2020, <https://vizhub.healthdata.org/gbd-compare/?fbclid=IwAR2wKFTCSeYbakfuufJbahlarj-UmejYfdHtVS9dhKcTgNDU-SM4TJfUf0>. 6. KBC Zagreb, News page, viewed 21 August 2020, <https://www.kbc-zagreb.hr/?s=zatajenja+crijevne+funkcije+>. 7. US National Library of Medicine, Clinical Trials.gov, Liver Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1232&map.y=392&recrs=adef&cond=Liver+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 8. US National Library of Medicine, Clinical Trials.gov, Renal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=1715>. 9. US National Library of Medicine, Clinical Trials.gov, Intestinal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1209&map.y=382&recrs=adef&cond=Intestinal+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 10. US National Library of Medicine, Clinical Trials.gov, Short Bowel Syndrome, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1199&map.y=387&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 11. Hrvatsko udruženje za Crohnovu bolest i Ulcerozni Kolitis. 2015. Homepage. Viewed 21 August 2020, <https://hucuk.hr/>. 12. Udruga oboljelih od Crohnove bolesti i ulceroznog kolitisa. 2019. Homepage. Viewed 21 August 2020, <http://www.colonos.hr/>. 13. PIRONI, L. et al. (2020). Home parenteral nutrition provision modalities for chronic intestinal failure in adult patients: An international survey. Clinical Nutrition. 39(2). 585-591. 14. Hrvatski zavod za zdravstveno osiguranje (HZZO) (2020), Home page, Hrvatski zavod za zdravstveno osiguranje (HZZO), viewed 21 August 2020, <https://www.hzzo.hr/en/>. † Indicated data found in non-English language sources. Information has been translated for inclusion.



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN THE CZECH REPUBLIC



COUNTRY CONTEXT	
Population ¹	10,625,250
Health expenditure (US\$ billion) ²	17.714
% government health expenditure ³	81.75%
% out-of-pocket expenditure ⁴	14.81%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5}	14/million per year (SBS-IF)
Chronic kidney disease prevalence (rate) ⁶	13,015/100,000
Chronic liver disease prevalence (rate) ⁶	15,689/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country? ⁷	YES

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	
- Liver failure ⁸	0
- Renal failure ⁹	12
- Intestinal failure ¹⁰ and short bowel syndrome ¹¹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Život bez střeva, z.s. ^{12†}	SBS

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹³	YES
Is HPN reimbursed in the country? ¹³	YES

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS ^{14,15†}	YES

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

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References: 1. The Global Cancer Observatory (2018), Czech Republic, World Health Organization, viewed 21 August 2020, <http://gco.iarc.fr/today/data/factsheets/populations/203-czechia-fact-sheets.pdf>. 2. Calculated by using the GDP (current US\$ billion) and the healthcare % share of GDP. 3. The World Bank, Domestic general government health expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 4. The World Bank, Out-of-pocket expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 5. BUDINSKA, E. et al. (2019), Microbiome and Metabolome Profiles Associated with Different Types of Short Bowel Syndrome: Implications for Treatment, Journal of Parenteral and Enteral Nutrition, 44(1), 105-118. 6. Institute for Health Metrics and Evaluation (IHME) (2017), GBD Compare | Viz Hub, Global Health Data Exchange, viewed 21 August 2020, <https://vizhub.healthdata.org/gbd-compare/?fbclid=IwAR2wKFTCSybakfuufJbahlarj-UmejYfdHtVS9dhKcTgNDU-SM4TJRJUF0>. 7. TESINSKY, P. et al. (2015), MON-PP197: Home Parenteral Nutrition National Registry in Czech Republic: Annual Report, Clinical Nutrition, 34, S201. 8. US National Library of Medicine, Clinical Trials.gov, Liver Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=1715>. 9. US National Library of Medicine, Clinical Trials.gov, Renal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1209&map.y=382&recrs=adef&cond=intestinal+failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 10. US National Library of Medicine, Clinical Trials.gov, Intestinal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1199&map.y=387&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 11. US National Library of Medicine, Clinical Trials.gov, Short Bowel Syndrome, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1199&map.y=387&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 12. Život bez střeva, 2020. Homepage, viewed 21 August 2020, <https://zivotbezstreva.cz>. 13. MORENO, J. et al. (2001), Survey on legislation and funding of Home Artificial Nutrition in Different European Countries, Clinical Nutrition 20(2), 117-123. 14. Společnost klinické výživy a intenzivní metabolické péče (SKVIMP) (2020), Doporučené postupy - Guidelines, Společnost klinické výživy a intenzivní metabolické péče (SKVIMP), viewed 21 August 2020, <http://www.skvimp.cz/podklady/doporucene-postupy-guidelines/>. 15. Společnost klinické výživy a intenzivní metabolické péče (SKVIMP) (2020), Doporučené postupy, Společnost klinické výživy a intenzivní metabolické péče (SKVIMP), viewed 21 August 2020, <http://www.skvimp.cz/pracovni-skupiny/domaci-parentalni-vyziva/doporucene-postupy/>. † Indicated data found in non-English language sources. Information has been translated for inclusion.



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN DENMARK



COUNTRY CONTEXT	
Population ¹	5,754,365
Health expenditure (US\$ billion) ^{2†}	27.2
% government health expenditure ³	84.02%
% out-of-pocket expenditure ⁴	13.74%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5}	~30/million (SBS)
Chronic kidney disease prevalence (rate) ⁶	9,646/100,000
Chronic liver disease prevalence (rate) ⁶	11,511/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country? ⁷	<input checked="" type="checkbox"/>
Is there an SBS-IF registry in the country? ⁸	<input checked="" type="checkbox"/>
Is there an HPN registry in the country? ⁷	<input checked="" type="checkbox"/>

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{7,9}	3

RESEARCH	
# clinical trials - Liver failure ¹⁰	6
# clinical trials (from 12/08/2010 to 12/08/2020) ^{**}	59
# clinical trials - Renal failure ¹¹	59
# clinical trials - Intestinal failure ¹² and short bowel syndrome ¹³	10

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
HPN Association ^{14†}	SBS-IF, HPN
CCF Association ^{15†}	IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁶	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ¹⁷	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF	<input type="button" value="NO INFO"/>
National guidelines: SBS	<input type="button" value="NO INFO"/>

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

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OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN ESTONIA



COUNTRY CONTEXT	
Population ¹	1,306,790
Health expenditure (US\$ billion) ^{2†}	1.9
% government health expenditure ³	74.66%
% out-of-pocket expenditure ⁴	23.66%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	19,692/100,000
Chronic liver disease prevalence (rate) ⁵	16,357/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	
- Liver failure ⁶	1
- Renal failure ⁷	6
- Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Eesti Pöletikulise Soolehaiguse Selts MTÜ ^{10†}	IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country?	NO INFO
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN FINLAND



COUNTRY CONTEXT	
Population ¹	5,542,526
Health expenditure (US\$ billion) ²	25.512
% government health expenditure ³	76.74%
% out-of-pocket expenditure ⁴	20.23%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	10,213/100,000
Chronic liver disease prevalence (rate) ⁵	12,833/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁶	1

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	0
- Liver failure ⁷	0
- Renal failure ⁸	17
- Intestinal failure ⁹ and short bowel syndrome ¹⁰	3

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Crohn ja Colitis ry ¹¹	IBD, GI

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹²	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN FRANCE



COUNTRY CONTEXT	
Population ¹	65,233,279
Health expenditure (US\$ billion) ²	314.079
% government health expenditure ³	77.09%
% out-of-pocket expenditure ⁴	9.38%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5}	3.6/million (HPN)
Chronic kidney disease prevalence (rate) ⁶	9,249/100,000
Chronic liver disease prevalence (rate) ⁶	11,979/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{7†}	18

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020) ^{**}	18
- Liver failure ⁸	18
- Renal failure ⁹	186
- Intestinal failure ¹⁰ and short bowel syndrome ¹¹	10

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
La Vie Par Un Fil ^{12†}	HAN, IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹³	YES <input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ¹⁴	YES <input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN GERMANY



COUNTRY CONTEXT	
Population ¹	82,293,462
Health expenditure (US\$ billion) ²	444.150
% government health expenditure ³	77.66%
% out-of-pocket expenditure ⁴	12.67%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5†}	34/million (HPN)
Chronic kidney disease prevalence (rate) ⁶	10,861/100,000
Chronic liver disease prevalence (rate) ⁶	13,880/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

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REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁷	24

RESEARCH	
# clinical trials - Liver failure ⁸	18
# clinical trials - Renal failure ⁹	205
# clinical trials - Intestinal failure ¹⁰ and short bowel syndrome ¹¹	5

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Selbsthilfe Kurzdarmsyndrom ^{12†}	SBS, IBD
Kindern in schwieriger Ernährungslage ^{13†}	SBS, IBD
Koordination Kurzdarmsyndrom ^{14†}	SBS, IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁵	<input checked="" type="checkbox"/> YES
Is HPN reimbursed in the country? ¹⁶	<input checked="" type="checkbox"/> YES

NATIONAL GUIDELINES	
National guidelines: CIF ^{17†}	<input checked="" type="checkbox"/> YES
National guidelines: SBS ^{18,19†}	<input checked="" type="checkbox"/> YES

CIF: Chronic Intestinal Failure
SBS-IF: Short Bowel Syndrome with Intestinal Failure
HPN: Home Parenteral Nutrition
IBD: Inflammatory Bowel Disease

Gt: Gastrointestinal
HAN: Home Artificial Nutrition
IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN HUNGARY



COUNTRY CONTEXT	
Population ¹	9,688,846
Health expenditure (US\$ billion) ²	10.870
% government health expenditure ³	68.74%
% out-of-pocket expenditure ⁴	26.89%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	13,604/100,000
Chronic liver disease prevalence (rate) ⁵	19,499/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	7
- Liver failure ⁶	7
# clinical trials - Renal failure ⁷	58
# clinical trials - Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
	NO INFO

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁰	YES
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN IRELAND



COUNTRY CONTEXT	
Population ¹	4,803,743
Health expenditure (US\$ billion) ²	27.428
% government health expenditure ³	73.29%
% out-of-pocket expenditure ⁴	12.28%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5}	9.6/million (HPN)
Chronic kidney disease prevalence (rate) ⁶	8,117/100,000
Chronic liver disease prevalence (rate) ⁶	14,137/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country? ⁷	YES

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	0
- Liver failure ⁸	0
- Renal failure ⁹	5
- Intestinal failure ¹⁰ and short bowel syndrome ¹¹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
	NO INFO

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ⁷	YES
Is HPN reimbursed in the country? ⁷	YES

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN ITALY



COUNTRY CONTEXT	
Population ¹	59,290,973
Health expenditure (US\$ billion) ²	184.226
% government health expenditure ³	73.90%
% out-of-pocket expenditure ⁴	23.49%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5}	14.12/million cases for people aged ≤19
Chronic kidney disease prevalence (rate) ⁶	10,170/100,000
Chronic liver disease prevalence (rate) ⁶	22,727/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country? ⁷	YES

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁵	19

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020) ^{**}	10
- Liver failure ⁸	105
- Renal failure ⁹	5
- Intestinal failure ¹⁰ and short bowel syndrome ¹¹	

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Un Filo per la Vita ^{12†}	HAN

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹³	YES
Is HPN reimbursed in the country? ¹⁴	YES

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

References: 1. The Global Cancer Observatory (2018), Italy, World Health Organization, viewed 21 August 2020, <http://gco.iarc.fr/today/data/factsheets/populations/380-italy-fact-sheets.pdf>. 2. Calculated by using the GDP (current US\$ billion) and the healthcare % share of GDP. 3. The World Bank, Domestic general government health expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 4. The World Bank, Out-of-pocket expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 5. DIAMANTI, A. et al. (2017). Pediatric Chronic Intestinal Failure in Italy Report from the 2016 Survey on Behalf of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP). Nutrients. 9(11). 6. Institute for Health Metrics and Evaluation (IHME) 2017, GBD Compare | Viz Hub, Global Health Data Exchange, viewed 21 August 2020, <https://vizhub.healthdata.org/gbd-compare/?fbclid=IwAR2wKFTCSeYbakiuufJbahlarij-UmeYfdHtVS9dhKcTgNDU-SM4TJPJUF0>. 7. LEZO, A. et al. (2018). Paediatric Home Artificial Nutrition in Italy: Report from 2016 Survey on Behalf of Artificial Nutrition Network of Italian Society for Gastroenterology, Hepatology and Nutrition (SIGENP). Nutrients. 10(9). 1311. 8. U.S National Library of Medicine, Clinical Trials.gov, Liver Failure, U.S National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1232&map.y=392&recrs=adef&cond=Liver+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 9. U.S National Library of Medicine, Clinical Trials.gov, Renal Failure, U.S National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=1715>. 10. U.S National Library of Medicine, Clinical Trials.gov, Intestinal Failure, U.S National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1209&map.y=382&recrs=adef&cond=Intestinal+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 11. U.S National Library of Medicine, Clinical Trials.gov, Short Bowel Syndrome, U.S National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1199&map.y=387&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 12. Un filo per la vita. 2020. Homepage. Viewed 21 August 2020, <http://www.unfiloperlavita.it/>. 13. PIRONI, L. et al. (2020). Home parenteral nutrition provision modalities for chronic intestinal failure in adult patients: An international survey. Clinical Nutrition. 39(2). 585-591. 14. MORENO, J. et al. (2001). Survey on legislation and funding of Home Artificial Nutrition in Different European Countries. Clinical Nutrition 20(2). 117-123. † Indicated data found in non-English language sources. Information has been translated for inclusion.



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN THE NETHERLANDS



COUNTRY CONTEXT	
Population ¹	17,084,467
Health expenditure (US\$ billion) ²	92.314
% government health expenditure ³	64.40%
% out-of-pocket expenditure ⁴	11.09%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{5,6}	3.7/million (HPN), 11.62/million (12.24 for adults, 9.56 for children) (CIF)
Chronic kidney disease prevalence (rate) ⁷	10,067/100,000
Chronic liver disease prevalence (rate) ⁷	13,761/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country? ⁶	<input checked="" type="checkbox"/> YES
Is there an SBS-IF registry in the country?	<input type="checkbox"/> NO INFO
Is there an HPN registry in the country? ^{8†}	<input checked="" type="checkbox"/> YES

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{9-12†}	4

RESEARCH	
# clinical trials - Liver failure ¹³	4
# clinical trials (from 12/08/2010 to 12/08/2020)**	52
# clinical trials - Renal failure ¹⁴	52
# clinical trials - Intestinal failure ¹⁵ and short bowel syndrome ¹⁶	4

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Crohn en Colitis Ulcerosa Vereniging Nederland (CCUVN) ^{17†}	SBS, IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁸	<input checked="" type="checkbox"/> YES
Is HPN reimbursed in the country? ^{19†}	<input checked="" type="checkbox"/> YES

NATIONAL GUIDELINES	
National guidelines: CIF	<input type="checkbox"/> NO INFO
National guidelines: SBS	<input type="checkbox"/> NO INFO

CIF: Chronic Intestinal Failure
SBS-IF: Short Bowel Syndrome with Intestinal Failure
HPN: Home Parenteral Nutrition
IBD: Inflammatory Bowel Disease
GI: Gastrointestinal
HAN: Home Artificial Nutrition
IV: Intravenous

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OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN NORWAY



COUNTRY CONTEXT	
Population ¹	5,353,365
Health expenditure (US\$ billion) ²	45.353
% government health expenditure ³	85.47%
% out-of-pocket expenditure ⁴	14.18%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	8,806/100,000
Chronic liver disease prevalence (rate) ⁵	11,717/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country? ⁶	NO
Is there an SBS-IF registry in the country? ⁶	NO
Is there an HPN registry in the country? ⁶	NO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials - Liver failure ⁷	0
# clinical trials (from 12/08/2010 to 12/08/2020)**	
# clinical trials - Renal failure ⁸	17
# clinical trials - Intestinal failure ⁹ and short bowel syndrome ¹⁰	2

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Norilco ^{11†}	GI
NIFO, Nosrk Intravenøs forening ^{12†}	HPN (IV general)
Landsforeningen mot fordøyelsessykdommer - LMF Norge ^{13†}	GI

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country?	NO INFO
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN POLAND



COUNTRY CONTEXT	
Population ¹	38,104,833
Health expenditure (US\$ billion) ²	38.324
% government health expenditure ³	68.97%
% out-of-pocket expenditure ⁴	23.05%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{5,6}	0.4/million (SBS) 1.1/million (HPN)
Chronic kidney disease prevalence (rate) ⁷	11,292/100,000
Chronic liver disease prevalence (rate) ⁷	14,527/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁸	1

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	2
- Liver failure ⁹	2
# clinical trials - Renal failure ¹⁰	83
# clinical trials - Intestinal failure ¹¹ and short bowel syndrome ¹²	5

** Please see page 1 for full search methodology.

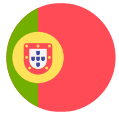
PATIENT ORGANISATIONS	
Apetyt na Życie (Appetite for Life) ^{13†}	IBD, HAN, GI

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁴	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ¹⁵	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
SBS-IF: Short Bowel Syndrome with Intestinal Failure
HPN: Home Parenteral Nutrition
IBD: Inflammatory Bowel Disease
GI: Gastrointestinal
HAN: Home Artificial Nutrition
IV: Intravenous

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OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN PORTUGAL



COUNTRY CONTEXT	
Population ¹	10,291,198
Health expenditure (US\$ billion) ²	21.618
% government health expenditure ³	66.25%
% out-of-pocket expenditure ⁴	27.53%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	10,942/100,000
Chronic liver disease prevalence (rate) ⁵	18,312/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	3
- Liver failure ⁶	3
- Renal failure ⁷	17
- Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
	NO INFO

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country?	NO INFO
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN ROMANIA



COUNTRY CONTEXT	
Population ¹	19,580,628
Health expenditure (US\$ billion) ²	12.384
% government health expenditure ³	78.59%
% out-of-pocket expenditure ⁴	20.49%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	11,906/100,000
Chronic liver disease prevalence (rate) ⁵	18,806/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence	NO INFO

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	5
- Liver failure ⁶	5
- Renal failure ⁷	37
- Intestinal failure ⁸ and short bowel syndrome ⁹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
	NO INFO

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁰	NO
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN SLOVAKIA



COUNTRY CONTEXT	
Population ¹	5,449,815
Health expenditure (US\$ billion) ²	7.144
% government health expenditure ³	79.10%
% out-of-pocket expenditure ⁴	18.71%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	11,497/100,000
Chronic liver disease prevalence (rate) ⁵	16,017/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{6†}	6

RESEARCH	
# clinical trials (from 12/08/2010 to 12/08/2020)**	3
- Liver failure ⁷	3
- Renal failure ⁸	11
- Intestinal failure ⁹ and short bowel syndrome ¹⁰	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
	NO INFO

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country?	NO INFO
Is HPN reimbursed in the country?	NO INFO

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 Gt: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN SLOVENIA



COUNTRY CONTEXT	
Population ¹	2,081,259
Health expenditure (US\$ billion) ²	4.423
% government health expenditure ³	71.82%
% out-of-pocket expenditure ⁴	12.33%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	12,883/100,000
Chronic liver disease prevalence (rate) ⁵	18,997/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{6,7}	3

RESEARCH	
# clinical trials - Liver failure ⁸	1
# clinical trials (from 12/08/2010 to 12/08/2020)**	8
# clinical trials - Renal failure ⁹	8
# clinical trials - Intestinal failure ¹⁰ and short bowel syndrome ¹¹	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
KVČB ^{12†}	IBD
Invalidsko društvo Kengurujček Slovenije ^{13†}	SBS, CIF

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁴	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ^{15†}	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN SPAIN



COUNTRY CONTEXT	
Population ¹	46,397,446
Health expenditure (US\$ billion) ²	125.87
% government health expenditure ³	70.62%
% out-of-pocket expenditure ⁴	23.57%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ⁵	5.1/million (HPN)
Chronic kidney disease prevalence (rate) ⁶	9,126/100,000
Chronic liver disease prevalence (rate) ⁶	17,898/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country? ^{7†}	YES
Is there an HPN registry in the country? ⁸	YES

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁹	6

RESEARCH	
# clinical trials - Liver failure ¹⁰	11
# clinical trials (from 12/08/2010 to 12/08/2020) ^{**}	
# clinical trials - Renal failure ¹¹	112
# clinical trials - Intestinal failure ¹² and short bowel syndrome ¹³	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
NUPA ^{14†}	SBS, IBD, IF
Asociación valenciana de niños con síndrome de intestino corto y dependientes de nutrición parenteral (ASVANIC) ^{15†}	SBS, IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁶	YES
Is HPN reimbursed in the country? ¹⁷	YES

NATIONAL GUIDELINES	
National guidelines: CIF ^{18†*}	YES
National guidelines: SBS ^{18†*}	YES

CIF: Chronic Intestinal Failure
SBS-IF: Short Bowel Syndrome with Intestinal Failure
HPN: Home Parenteral Nutrition
IBD: Inflammatory Bowel Disease
GI: Gastrointestinal
HAN: Home Artificial Nutrition
IV: Intravenous

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References: 1. The Global Cancer Observatory (2018), Spain, World Health Organization, viewed 21 August 2020, <https://gco.iarc.fr/today/data/factsheets/populations/724-spain-fact-sheets.pdf>. 2. Calculated by using the GDP (current US\$ billion) and the healthcare % share of GDP. 3. The World Bank, Domestic general government health expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.GHED.CH.ZS>. 4. The World Bank, Out-of-pocket expenditure (% of current health expenditure), The World Bank, viewed 21 August 2020, <https://data.worldbank.org/indicator/SH.XPD.OOPC.CH.ZS>. 5. KELLY, DG. et al. (2014). Short bowel syndrome: highlights of patient management, quality of life, and survival. JPEN Parenter Enteral Nutr. 38(4). 427-37. 6. Institute for Health Metrics and Evaluation (IHME) (2017), GBD Compare | Viz Hub, Global Health Data Exchange, viewed 21 August 2020, <https://vizhub.healthdata.org/gbd-compare/?fbclid=IwAR2wKFTCSeybakfuufJbahlarj-UmejYfdHtVS9dhKcTgNDU-SM4TJPUJf0>. 7. Spanish Rare Diseases Registries Research Network Instituto de Salud Carlos III, viewed 21 August 2020, <https://spaindriscii.es/Paginas/default.aspx>. 8. WANDEN-BERGHE, C. et al. (2018). Home and Ambulatory Artificial Nutrition (NADYA) Report. Home Parenteral Nutrition in Spain. Clinical Nutrition. 35(6), 1491-1496. 9. STAJN, M. et al. (2007). Management of intestinal failure in Europe. A questionnaire-based study on the incidence and management. Dynamic Medicine. 6(1). 10. US National Library of Medicine, Clinical Trials.Gov, Liver Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 11. US National Library of Medicine, Clinical Trials.Gov, Renal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=887&map.y=280&recrs=adef&cond=Renal+Insufficiency&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=1715>. 12. US National Library of Medicine, Clinical Trials.Gov, Intestinal Failure, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=1209&map.y=382&recrs=adef&cond=Intestinal+Failure&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 13. US National Library of Medicine, Clinical Trials.Gov, Short Bowel Syndrome, US National Institute of Health, 2020, viewed 14 August 2020, <https://clinicaltrials.gov/ct2/results/map/click?map.x=387&map.y=382&recrs=adef&cond=Short+Bowel+Syndrome&strd_s=12%2F08%2F2010&strd_e=12%2F08%2F2020&mapw=2351>. 14. Asociación de niños, adultos y familias con fallo intestinal, nutrición parenteral y trasplante múltiple. 2020. Homepage. Viewed 21 August 2020, <https://somosnupa.org/>. 15. Asociación valenciana de niños con síndrome de intestino corto y dependientes de nutrición parenteral. 2020. Homepage. Viewed 21 August 2020, <https://www.solucionesong.org/ong/asociacion-valenciana-de-ninos-con-sindrome-de-intestino-corto-y-dependientes-de-nutricion-parenteral-asvanic/10160/view>. 16. PIRONI, L. et al. (2020). Home parenteral nutrition provision modalities for chronic intestinal failure in adult patients: An international survey. Clinical Nutrition. 39(2), 585-591. 17. DREESSEN, M. et al. (2013). Development of quality of care interventions for adult patients on home parenteral nutrition (HPN) with a benign underlying disease using a two-round Delphi approach. Clinical Nutrition. 32(1), 59-64. 18. SEGHNIP Sociedad Española de Gastroenterología Pediátrica, viewed 21 August 2020 <https://www.seghnp.org/documentos?field_tipo_documento_target_id_1=1>. † Indicated data found in non-English language sources. Information has been translated for inclusion. ‡ Paediatric guidelines.



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN SWEDEN



COUNTRY CONTEXT	
Population ¹	9,982,703
Health expenditure (US\$ billion) ²	61.271
% government health expenditure ³	83.69%
% out-of-pocket expenditure ⁴	15.03%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	11,234/100,000
Chronic liver disease prevalence (rate) ⁵	13,469/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁶	1

RESEARCH	
# clinical trials - Liver failure ⁷	3
# clinical trials (from 12/08/2010 to 12/08/2020)**	62
# clinical trials - Renal failure ⁸	62
# clinical trials - Intestinal failure ⁹ and short bowel syndrome ¹⁰	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Hem Parenteral Nutrition (HPN) ^{11†}	HAN, GI
ILCO ^{12†}	GI

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹³	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ¹⁴	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF ^{15†}	<input checked="" type="checkbox"/>
National guidelines: SBS ^{15†}	<input checked="" type="checkbox"/>

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous

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OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN SWITZERLAND



COUNTRY CONTEXT	
Population ¹	8,544,026
Health expenditure (US\$ billion) ²	87.068
% government health expenditure ³	30.49%
% out-of-pocket expenditure ⁴	28.95%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate)*	NO INFO
Chronic kidney disease prevalence (rate) ⁵	9,788/100,000
Chronic liver disease prevalence (rate) ⁵	11,768/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country?	NO INFO
Is there an SBS-IF registry in the country?	NO INFO
Is there an HPN registry in the country?	NO INFO

REFERENCE CENTRES	
# reference centres/ centres of excellence ⁶	1

RESEARCH	
# clinical trials - Liver failure ⁷	2
# clinical trials (from 12/08/2010 to 12/08/2020)**	37
# clinical trials - Renal failure ⁸	37
# clinical trials - Intestinal failure ⁹ and short bowel syndrome ¹⁰	0

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Magendarmliga Schweiz ^{11†}	IBD
Crohn Colitis Switzerland ^{12†}	Crohn's disease and IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ^{13†}	<input checked="" type="checkbox"/> YES
Is HPN reimbursed in the country? ^{13†}	<input checked="" type="checkbox"/> YES

NATIONAL GUIDELINES	
National guidelines: CIF	NO INFO
National guidelines: SBS	NO INFO

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
 IBD: Inflammatory Bowel Disease
 GI: Gastrointestinal
 HAN: Home Artificial Nutrition
 IV: Intravenous



OVERVIEW OF THE INTESTINAL FAILURE LANDSCAPE IN THE UNITED KINGDOM



COUNTRY CONTEXT	
Population ¹	66,573,503
Health expenditure (US\$ billion) ²	274.937
% government health expenditure ³	79.41%
% out-of-pocket expenditure ⁴	15.96%

DISEASE BURDEN/EPIDEMIOLOGY	
CIF/SBS-IF prevalence (rate) ^{*5,6}	3.7/million (HPN), 21/million HPN - point prevalence and includes home IV fluids. (This rises to nearer 40/million if including home care company data)
Chronic kidney disease prevalence (rate) ⁷	8,459/100,000
Chronic liver disease prevalence (rate) ⁷	14,071/100,000

* Where CIF/SBS-IF prevalence is not available, HPN prevalence is provided as an indicator-only. Not all HPN patients are CIF/SBS-IF patients.

REGISTRIES	
Is there a CIF registry in the country? ⁸	<input checked="" type="checkbox"/>
Is there an SBS-IF registry in the country? ⁸	<input checked="" type="checkbox"/>
Is there an HPN registry in the country? ⁸	<input checked="" type="checkbox"/>

REFERENCE CENTRES	
# reference centres/ centres of excellence ^{9,10}	2

RESEARCH	
# clinical trials - Liver failure ¹¹	12
# clinical trials (from 12/08/2010 to 12/08/2020)**	175
# clinical trials - Intestinal failure ¹³ and short bowel syndrome ¹⁴	8

** Please see page 1 for full search methodology.

PATIENT ORGANISATIONS	
Patients on Intravenous and Naso-gastric Nutrition Treatment (PINNT) ¹⁵	SBS, GI, HAN, IBD
Short Bowel Survivors and Friends ¹⁶	SBS, GI, HAN, IBD

HPN AVAILABILITY & REIMBURSEMENT	
Is HPN available in the country? ¹⁷	<input checked="" type="checkbox"/>
Is HPN reimbursed in the country? ¹⁸	<input checked="" type="checkbox"/>

NATIONAL GUIDELINES	
National guidelines: CIF ¹⁹	<input checked="" type="checkbox"/>
National guidelines: SBS ¹⁹	<input checked="" type="checkbox"/>

CIF: Chronic Intestinal Failure
 SBS-IF: Short Bowel Syndrome with Intestinal Failure
 HPN: Home Parenteral Nutrition
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