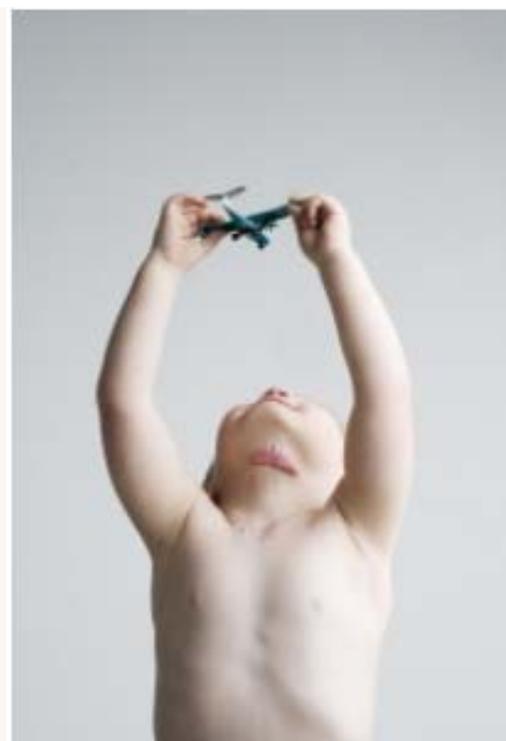
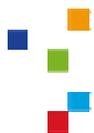


SYNTHESIS

ORGANISATION OF AFTERCARE FOR PATIENTS WITH SEVERE BURN INJURIES





Belgian Health Care Knowledge Centre

The Belgian Health Care Knowledge Centre (KCE) is an organization of public interest, created on the 24th of December 2002 under the supervision of the Minister of Public Health and Social Affairs. KCE is in charge of conducting studies that support the political decision making on health care and health insurance.

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SYNTHESIS

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Cover picture	Picture at the right: Lieve Blancquaert (http://www.lieveblancquaert.be/portfolio/mijn-zachtste-huid/175)



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- **Finally, this report has been approved by common assent by the Executive Board.**
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■ FOREWORD

Burn injuries provoke spontaneously the image of an acute trauma: emergency care, with if necessary intensive care, specialized wound care and possibly skin-grafting ... after which the patient recovers with scars that are more or less pronounced. It is far less known that the acute care phase is followed by a long and intensive rehabilitation process. A severe burn injury can, as such, be considered as a chronic condition but with a different evolution over time; a (super-) acute onset, followed by a usually long period of decreasing care needs: wearing pressure garments; applying ointments several times a day; reconstructive surgery, mobilizing and manipulating the burned limbs; etc. The decreasing physical care needs often coincide with an increasing need for psychological support: as time passes, it becomes clearer to patients that the scars, the discomfort, the functional limitations and financial consequences are often there for life. On top of that patients experience a difficult process of reintegration and often have to face societal prejudices and stigmatization, especially in case of visible scars.

A burn injury can happen to everyone, but the most vulnerable people in our society are more at risk: children, often very young, elderly already being care dependent, underprivileged already financially burdened.

Our country has a number of highly specialized and also renowned burn care centres that are successful in guiding patients, even with very severe burn injuries, through the acute care phase. The post-acute care phase is far less structured and standardized. Usually, patients (and their parents in case of children) have to find their own way in the existing care offer. In all respects there is (not yet) a general accepted optimal care pathway (or, even better, a cluster of care pathways) and the accessibility to adequate rehabilitation care remains unequal.

Conform its core mission, the Belgian Burn Foundation, submitted this research topic to the KCE and continued to render their cooperation during this project. But also the remarkably united input from the numerous collaborators of the burn care centres, from patients of all ages (including children and their parents) and other experts and stakeholders were key to the success of this research project. It has been a fascinating exercise, liberating a lot of goodwill on the field, and we would like to express our gratitude to all participants.

The next challenge is to make the 12 recommendations that emerged from this exercise tangible for the burn survivors of today and tomorrow!

Christian LÉONARD
Deputy general director

Raf MERTENS
General director



■ ABSTRACT

BACKGROUND

Since the 1960's, most western countries developed specific burn care centres with architectural provisions for isolation and climate control and large amounts of expert dedicated personnel to care for patients with severe burn injuries. In Belgium there are 6 burn care centres with a total of 70 beds. These burn care centres focused, historically, mainly on the acute, critical care phase. This approach contributed substantially to the decreasing mortality rate among patients with burn injuries. A severe burn injury can impact on all aspects of a person's life, including their aesthetic appearance, financial situation, relationships with others, psychological, social (e.g. integration work/school) and physical functioning. Due to the increased survival rate of severely burned patients more patients need a long-term multidisciplinary rehabilitation process.

OBJECTIVE

The overall aim of this report is to formulate points for improvement of the organization of aftercare (i.e. care process after discharge from the burn care centre) for patients with severe burn injuries. The report addresses four research questions:

1. What is the incidence of patients with severe burn injuries in Belgium?
2. How is the current organization and payment of aftercare for patients with severe burn injuries?
3. Which are the specific problems for patients with severe burn injuries during aftercare and which are the unmet care needs (if any) according to patients, healthcare professionals and representatives of burn organisations?
4. Are clinical guidelines available to allow the identification of clinical key interventions?

The results of this study can be used as input for the development of a care program for patients with severe burn injuries, a process recently initiated by the National Institute for Health and Disability Insurance (RIZIV - INAMI) and the Federal Public Service Health, Food Chain Safety and Environment (FOD - SPF).



METHODS

This study combined various methods: analysis of administrative databases (i.e. Hospital Discharge Dataset: MZG - RHM, Hospital Billing Records: AZV - SHA, extraction of the electronic medical record of the Military Hospital); a SWOT-analysis based on in-depth interviews with patients (n=29), physicians (n=7), representatives of patient organisations (n=4) and focus groups with allied health professionals (n=17); a scoping literature review including peer-reviewed articles and grey literature; extensive consultation of a broad selection of stakeholders about the proposed solution elements (n=30).

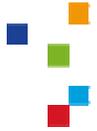
RESULTS

This study identified several well-intended and well-executed bottom-up local initiatives that aim to support patients with severe burn injuries during their rehabilitation to improve their reintegration. However, these initiatives are rarely embedded at the system's level. In addition, several problem areas were identified at the systemic level, indicating there is room for improvement:

- Knowledge problems:
 - There is a lack of basic epidemiological data about patients with severe burn injuries. Since the numerous limitations of the routinely collected administrative databases (e.g. coding practices, data quality) do not allow obtaining accurate results on the incidence of (severe) burn injuries in Belgium.
 - There is an absence of methodological soundly developed (evidence-based) guidelines.
 - Aftercare for most patients typically includes outpatient visits in burn care centres and services provided by primary care providers (e.g. nurses, physiotherapists, psychologists). However, the lack of multidisciplinary collaboration and lack of burn care specific competencies among healthcare providers in primary care have been identified as a major weakness in the current system.

- Organisational problems:
 - There is a sub-optimal use of critical care beds of the burn care centres. On one hand, not all patients with severe burn injuries are (timely) treated in a burn care centre. On the other hand, critical care beds of burn care centres are used for patients with burn injuries (no longer) requiring critical care.
 - There is a lack of standardization of care processes. Examples are the lack of uniform discharge policies and procedures and the observed heterogeneity in the type of professional disciplines involved in follow-up and aftercare.
- Problems with payment systems:
 - The existing predominantly fee-for-service payment system hinders a multidisciplinary long-term follow up since reimbursement rules are too restrictive. Occupational therapists, for instance, can give support to the reintegration but they are only accessible to a minority of patients who have been treated in rehabilitation centers. Another example is the absence of reimbursement for ambulatory psychological care.

Despite the different mechanisms (e.g. maximum billing system) to protect the financial accessibility of the Belgian healthcare system the financial impact of a burn injury can be serious since many products (e.g. ointments, wound care products) and services are not included in these systems.



CONCLUDING REMARKS

This research project has given to patients, healthcare providers, patient organisations and other stakeholders the opportunity to reflect on the strengths and weaknesses of the current organisation and payment of the services for patients with severe burn injuries. This study showed that the burn care sector struggles with numerous (and often interrelated) problems to organize the post-acute care for patients with severe burn injuries.

In this report, specific initiatives positive well executed local initiatives are described that would benefit from coordination and harmonization at the macro-level to provide an accessible, equitable support to all patients. Reforms of current payment systems are important in this context as well.

The propositions (i.e. 12 recommendations) should be considered as a cluster of interdependent solution elements. The process of change is likely to be a lengthy one, and this research represents only one step along that road. The next step would be to transform these recommendations into more concrete actions and reforms.



■ SYNTHESIS

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1. INTRODUCTION

1.1. Patients with burn injuries: a heterogeneous population

Burns range from minor burns to devastating injuries with the severity depending on several factors such as age, depth and surface area of the lesion, body region, simultaneous smoke inhalation and previous health conditions.¹ Different classification systems exist to distinguish burns: the systems based on mechanism or cause, on the degree or depth of the burn and on the 'Total Body Surface Area' (TBSA) burned are the most common ones (see Table 2). Nevertheless, there is no consensus on a definition of "patients with severe burn injuries". Therefore in this study we rely on the legal criteria for admission or referral to a burn care centre (see text box). Patients with 'Lyell syndrome' (criterion 10) are out of scope of the current study since these patients have very different aftercare needs.

Legal criteria for admission or referral to a Belgian burn care centre as defined in the Royal Decree of March 2007^a: patients meeting one of the following criteria are eligible for admission on a burn care centre.

- **Criterion 1: Second degree burns larger than 10 % of the TBSA and third degree burns for patients up to 10 years old and more than 49 years old;**
- **Criterion 2: Second and third degree burns larger than 20 % TBSA;**
- **Criterion 3: Third degree burns larger than 5 % TBSA;**
- **Criterion 4: Significant burns that involve face, hands, feet, genitalia, perineum or the major joints;**
- **Criterion 5: Electrical or chemical burns;**
- **Criterion 6: Inhalation injuries (Bronchi, Alveoli, ...);**

^a Based on Article 2 of the Royal Decree of 19 march 2007 (published 13/04/2007)

- **Criterion 7: Burn injuries in patients with pre-existing medical disorders that could complicate treatment management or influence the recovery or the mortality;**
- **Criterion 8: Burn injuries in patients who will require special social or emotional intervention, including neglected or abused children;**
- **Criterion 9: Burn associated with concomitant significant trauma or burn with great local complications;**
- **Criterion 10: Lyell syndrome (toxic epidermal necrolysis or Staphylococcal scalded skin syndrome);**
- **Criterion 11: Major traumatic or medical epidermal necrolysis (gangrene, necrotizing fasciitis,...) larger than 10 % TBSA.**

1.2. A relatively small patient population, few epidemiological data

There is a paucity of epidemiological data as most European countries do not have a national burn register.² Nevertheless a recent systematic review summarized the available European data based on peer reviewed publications.³ They defined a 'severe' burn injury as an acute burn injury needing specialized care during a hospital admission. The reported annual incidence of patients with severe burn injuries, in the 14 included studies with data from 10 different countries, lies between 0.2 and 2.9/10 000 inhabitants.³ This is only a fraction of the total burn injuries since it is reported that only 5% of the patients with non-fatal burn injuries require treatment in specialized burn care centres.⁴

Children younger than 16 years account for almost half of the population with severe burn injuries. Children younger than 5 years account for 50% to 80% of all childhood burns. At the other end of the age spectrum an increased proportion of elderly is observed (10 to 16% of the total population with severe burn injuries). Males (55 to 75%) represent the majority of patients with severe burn injuries. In addition to age and gender, lower socioeconomic status and ethnic minority groups are also reported to have a higher risk on burn injury.^{4, 5} Flames, scalds and contact burns are the top three causes of severe burns, but in children scalds clearly dominate.³



1.3. Burn care centres: main focus on the acute care phase

Since the 1960's, efforts in most western countries focused on the critical care phase with the development of specific burn care centres with large amounts of expert dedicated personnel and architectural provisions for isolation and climate control. In Belgium there are 6 burn care centres with a total of 70 beds (see Table 1). Five of the six burn care centres are part of general hospitals. The situation of the Military hospital is different since it falls within the competences of the Ministry of Defence and not under the Federal Public Service Health, Food Chain Safety and Environment (FOD - SPF).

The organization of care for patients with severe burn injuries in large specialized burn care centres contributed substantially to the decreasing mortality rate.⁶ Nowadays, due to the successful battle against infections and the improvements in medical techniques, patients with even massive burn injuries (>80%TBSA) have sometimes a chance of survival.⁷

Table 1 – Belgian burn care centres

Hospital	Number of hospital beds
Militair Hospitaal Koningin Astrid/ l'Hôpital Militaire Reine Astrid (Neder-Over-Heembeek)	26 beds (8 high-care, 14 medium care and 4 low risk)
Ziekenhuis Netwerk Antwerpen	10 beds
UZ Gent	6 beds
UZ Leuven	12 beds
CHU de Liège	6 beds
Grand Hôpital de Charleroi (IMTR, Loverval)	10 beds

1.4. Need for expanding the service offer to aftercare services

A severe burn injury can impact on all aspects of a person's life, including their aesthetic appearance, financial situation, relationships with others, psychological, social (e.g. integration work/school) and physical functioning.⁸ Due to the increased survival rate of severely burned patients more patients need a long-term multidisciplinary rehabilitation process.⁷⁻⁹

The rehabilitation process begins with the admission to the burn care centre.¹⁰ The care process after discharge from the burn care centre is often referred to as 'Aftercare'.⁷ This typically includes outpatient visits in hospitals (mainly in burn care centres) and services provided by primary care providers (e.g. nurses, physiotherapists, psychologists). However, the care process of burn patients is not restricted to a stay in a burn care centre and/or the aftercare services mentioned above. It can, for instance, include the treatment in step-down units (e.g. paediatric unit, general surgical unit) or the referral to specific rehabilitation centres for multidisciplinary recovery. The continuity of care between specialized burn units, step-down units and rehabilitation wards are therefore also within the scope of this study.

Table 2 – Classification system of Burns

Classification of Burns¹¹

Classification by mechanism or cause:

Thermal burns involve the skin and may present as:

- scalds – caused by hot liquid or steam;
- contact burns – caused by hot solids or items such as heaters, hot pressing irons and cooking utensils, as well as lighted cigarettes;
- flame burns – caused by flames or incandescent fires, such as those started by lighted cigarettes, candles, lamps or stoves;
- chemical burns – caused by exposure to reactive chemical substances such as strong acids or alkalis;
- electrical burns – caused by lightening or an electrical current passing from an electrical outlet, cord or appliance through the body.



Inhalational burns are the result of breathing in superheated gases, steam, hot liquids or noxious products of incomplete combustion.

Classification by the degree and depth of burn:

First-degree or superficial burns are defined as burns to the epidermis that result in a simple inflammatory response. They are typically caused by exposure of the unprotected skin to solar radiation (sunburn) or to brief contact with hot substances, liquids (scalds) or flash flames. First-degree burns heal within a week with no permanent changes in skin colour, texture, or thickness.

Second-degree or partial-thickness burns result when damage to the skin extends beneath the epidermis into the dermis. The damage does not, however, lead to the destruction of all elements of the skin.

– Superficial second-degree burns (limited to epidermis or superficial dermis) are those that take less than three weeks to heal.

– Deep second-degree burns (lesion extended into deep dermis) take more than three weeks to close and are likely to form hypertrophic scars.

Third-degree or full-thickness burns are those where there is damage to all skin elements – including epidermis, dermis, and deep hair follicles. It can also affect the subcutaneous tissue layer. As a result of the extensive destruction of the skin layers, third-degree burn wounds cannot regenerate themselves without grafting.

Classification by extent of burn:

The extent of burn, clinically referred to as the total body surface area (TBSA) burned, is defined as the proportion of the body burned. Several methods are used to determine this measurement, of which the most common are the so-called “rule of nines” and the Lund and Browder Chart. The “rule of nines” method assigns 9% to the head and neck region, 9% to each arm (including the hand), 18% to each leg (including the foot) and 18% to each side of the trunk (back, chest and abdomen). In Belgium there is consensus to use the Lund and Browder. The calculation assumes that the size of a patient’s palm (including the fingers) is roughly 1% of the total body surface area.¹²

1.5. Objective: to formulate points for improvement for the organization of aftercare services for patients with severe burn injuries

The overall aim of this report is to formulate points for improvement of the organization of aftercare for patients with severe burn injuries. The report addresses four research questions:

1. What is the incidence of patients with severe burn injuries in Belgium?
2. How is the current organization and payment of aftercare for patients with severe burn injuries?
3. Which are the specific problems for patients with severe burn injuries during aftercare and which are the unmet care needs (if any) according to patients, healthcare professionals and representatives of burn organisations?
4. Are clinical guidelines available to allow the identification of clinical key interventions?

This study combined various methods:

- Analysis of administrative databases (e.g. identifying number of patients with severe burn injuries, length-of-stay on burn care centres): Hospital Discharge Dataset (MZG - RHM), Hospital Billing Records (AZV - SHA), extraction of the electronic medical record of the Military Hospital.
- Qualitative research: interviews and focus groups with patients (n=29), physicians (n=7), allied health professionals (n=17) and representatives of patient organisations (n=4); stakeholder consultation (n=30).
- A scoping literature review including peer-reviewed articles and grey literature to identify (inter-)national best practices.

The results of this study can be used as input for the development of a care program for patients with severe burn injuries, a process recently initiated by the National Institute for Health and Disability Insurance (RIZIV - INAMI) and the Federal Public Service Health, Food Chain Safety and Environment (FOD - SPF).



2. PATIENTS WITH SEVERE BURN INJURIES IN BELGIAN HOSPITALS: CURRENT DATABASES ARE INACCURATE

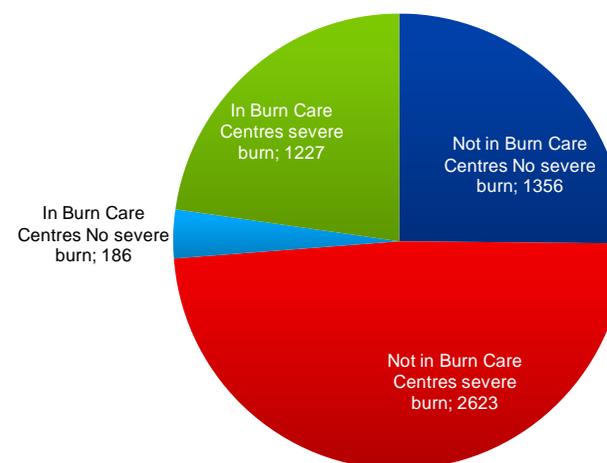
There are **no accurate data available about patients with severe burn injuries in Belgian hospitals**. The first problem is that there is no (inter-)national validated definition of 'severe burn injuries'. Relying on the legal admission criteria¹³ includes a risk of over-estimating as well as under-estimating the number of patients with severe burn injuries. After all, stakeholders confirmed that some of the admission criteria were too liberal (possibly resulting in the admission of non-severe burn injuries on burn care centres) while others are too restrictive (possibly hampering the admission of severe burn injuries on burn care centres).

A second problem is that we used administrative databases (i.e. MZG - RHM and AZV - SHA), initially not designed for such analysis. General limitations of administrative databases are problems with variation in coding practices, up-coding and linking problems between different databases.¹⁴ In this study an additional particular problem emerged. Some of the legal admission criteria for burn care centres (i.e. criteria 5 to 9; 11) could not be transformed in coding language that is used in the administrative databases potentially resulting in 'false negative cases'. In addition, for criterion 4 "Significant" burns could not be computed as such and therefore all burns involving face, hands, feet, genitalia, perineum or major joints – whatever the degree or the % of surface burned – were considered as meeting criterion 4. It is likely that this results in a substantial number "false positive" cases (i.e. burn injuries that are not significant).

A third problem is that the routinely collected databases are not available for the Military Hospital. We therefore, used a data extraction of the Military hospital data warehouse which cannot be compared with the administrative databases (e.g. different years, different registration rules and coding practices).

Given all these limitations all presented data should therefore be considered as **rough estimates to be interpreted with caution**.

Figure 1 – Number of stays for burn injuries by severity status (Period 2008-2009)^b



^b Based on administrative databases MZG- RHM / AZV-SHA (Military Hospital not included)



Based on our algorithm a total of 3 850 stays (years 2008-2009) were flagged as hospital stays of patients with severe burns (32% in burn care centres; 68% outside burn care centres). The large number of flagged hospital stays for patients with severe burn injuries treated outside the burn care centres (i.e. 2623 stays) is mainly due to criterion 4 (72% or 1898 cases) and includes probably a high number of false positive cases. Nevertheless, even for the most severe criterion (i.e. criterion 2 second and third degree burns larger than 20% TBSA) 52 patients were treated outside a burn care centre and only 17 of them were transferred to another hospital (the data analysis did not allow to identify that these 17 patients were transferred to a burn care centre).

Our data analysis showed that 44% of stays selected on burn care centres does not have a (primary or secondary) diagnosis corresponding to a burn injury. It was confirmed during stakeholder contacts that some burn care centres use this capacity as general intensive care units beds when these beds are not needed for the treatment of patients with severe burn injuries. From the 1 413 burn injury related hospital stays on one of the five burn care centres with administrative databases, 1 227 (87%) are labelled as 'severe' burn injuries. The median (Q1-Q3) length of stay for patients with severe burn injuries that were treated on burn care centres was 4 days (1-18 days). Overall, very young children (0-5 years) are proportionally most impacted by severe burns (20% of stays in Burn care centres).

For the Military hospital we identified 371 cases (year 2012) with 75% of the cases having a TBSA of less than 10%. The median (Q1-Q3) length of stay was 8 days (3-20 days).

3. PROBLEM AREAS

This study identified several well-intended and well-executed bottom-up local initiatives that aim to support patients with severe burn injuries during their rehabilitation. However, these initiatives are rarely embedded at the system's level. In addition, several problem areas were identified at the systemic level, indicating there is room for improvement:

- Knowledge problems:
 - There is a lack of basic epidemiological data about patients with severe burn injuries. Since the numerous limitations of the routinely collected administrative databases (e.g. coding practices, data quality) do not allow obtaining accurate results on the incidence of (severe) burn injuries in Belgium.
 - There is an absence of methodological soundly developed (evidence-based) guidelines.
 - Aftercare for most patients typically includes outpatient visits in burn care centres and services provided by primary care providers (e.g. nurses, physiotherapists, psychologists). However, the lack of multidisciplinary collaboration and lack of burn care specific competencies among healthcare providers in primary care have been identified as a major weakness in the current system.
- Organisational problems:
 - There is a sub-optimal use of critical care beds of the burn care centres. On one hand, not all patients with severe burn injuries are (timely) treated in a burn care centre. On the other hand, critical care beds of burn care centres are used for patients with burn injuries (no longer) requiring critical care.
 - There is a lack of standardization of care processes. Examples are the lack of uniform discharge policies and procedures, the observed heterogeneity in the type of professional disciplines involved in follow-up and aftercare and differences in the implementation of the care coordinator role. This variation between and within burn care centres contributes to inequity in the services offer.



- Problems with payment systems:
 - The existing predominantly fee-for-service payment system hinders a multidisciplinary long-term follow up since reimbursement rules are too restrictive. Occupational therapists, for instance, can give support to the reintegration but they are only accessible to a minority of patients who have been treated in rehabilitation centers. Another example is the absence of reimbursement for ambulatory psychological care.
 - Despite the different mechanisms (e.g. maximum billing system) to protect the financial accessibility of the Belgian healthcare system the financial impact of a burn injury can be serious since many products (e.g. ointments, woundcare products) and services are not included in these systems.

4. RECOMMENDATIONS FOR A MORE EFFECTIVE ORGANISATION OF AFTERCARE SERVICES FOR PATIENTS WITH SEVERE BURNS

The following sections propose measures and reforms to improve the current system. These recommendations are based on elements that emerged from:

- The analysis of the Belgian situation and identified problem areas.
- The stakeholder encounters.
- Other Belgian health care initiatives outside the burn care domain.
- The review of best practices abroad.
- Previous KCE-reports, in particular the KCE-report on chronic care.¹⁵ Patients with burn injuries have also specific, changing care needs (biological, psychological...) during a long period. The difference is that burn patients face a very acute onset and are gradually improving, while for most chronic diseases there is a gradual deterioration.

A draft version of these recommendations was submitted to a broad selection of experts and stakeholders in September 2013. The proposed recommendations were on the whole received as relevant and in accordance with the scope of the reform that stakeholders were anticipating.



4.1. Burn care structures and their organisation

4.1.1. Set up an all-encompassing burn care network structure

Recommendation 1

In order to reduce the fragmentation in care and to promote an integrated care process for the burn patients, all structures involved in the care for burn patients should be integrated into a two-layered burn care network:

- **Each Burn care centre should become the central node of a Regional Burn Care Network.**
- **A National Network for Burns should be the overarching structure over the regional networks.**

The Regional Burn Care Network is built around the burn care centre as a central node. At present, there are 6 burn care centres with 70 beds. When accurate data become available (see 4.4.3) it should be evaluated whether this capacity is in accordance with the actual needs.

A network should bring together all the care that is required, at the right time, in function of the patient needs. It should include step-down units (for referral and back-referral), rehabilitation centres and a network of multidisciplinary primary care professionals. In addition the network should also include general hospitals with emergency rooms to ensure adequate referrals and back referrals (see 4.1.2.).

Models from abroad, such as the British Burn Care Networks, can be a source of inspiration but should be adapted to the Belgian reality. The British networks are geographically organized and NHS Burn care service providers are structured in three levels of care that work collaboratively:

- *Burn care centres*: geographically discrete wards offering the highest level of critical care.
- *Burn units*: separately staffed discrete wards targeting patients with a moderate level of injury complexity.
- *Burn care facilities*: general plastic surgical wards for the non-complex burn injuries.

Burn care services work in collaboration with their local hospital emergency departments to ensure patients are accurately assessed and referred to the right specialized care provider.

The effective implementation of a network structure depends on the following points: adequate payment structures (4.4.1.); service level agreements that clearly define roles and responsibilities; development of multidisciplinary cross-sectional pathways based on (inter-)national guidelines (see 4.3.); the use of a shared electronic patient record (see 4.1.3.); dedicated professionals (care coordinators) to coordinate the care process; performance evaluation at the network level (e.g. monitoring of patient outcomes: see 4.4.3).

The National Network for Burns should be the overarching structure, monitoring the regional networks. It should develop a number of transversal activities such as the development of referral standards, common guidelines, professional standards, uniform description and quality criteria for the care coordinator role, bundled payment agreements.

It should include representatives of the Burn care centres, RIZIV – INAMI, FOD - SPF and the Belgian Burns foundation, and should have a structural link with the College of physicians in burn care (to be set up; see below).

Currently, the Belgian association for burn injuries already offers a common platform to the Burn care centres. It is recommended to transform this organization into a college of physicians in burn care under the auspices of the FOD - SPF with a formal mandate to promote quality of care within the domain of burn care.

The National Network should be chaired by an organization/person independent from the burn care centres.

4.1.2. Entry into the (acute) care process

The efficient and effective management of the entry into the care process is key to optimize the care in the post-acute phase. Healthcare professionals stressed the importance of specialized dedicated multidisciplinary input and appropriate facilities during the acute phase to prevent problems (e.g. hypertrophic scars) in the post-acute phase (see scientific report: 4.3.2.2.). In addition, patients with severe burn injuries not treated in a burn care centre during the acute phase are reported to have limited access to aftercare or not to receive the full range of services (see scientific report: 4.3.9.13.). Managing the access of patients with severe



burn injuries into the care process (i.e. treatment in a burn care centre) is, therefore, an important system's goal.

Recommendation 2

The entry of burn patients into the acute care process should be managed in a more effective way.

A 'National Burn Care Referral Guidance' should be developed, to support all hospitals that admit emergency patients to appropriately refer patients with severe burn injuries immediately to a burn care centre.

Physicians working in emergency units should be specifically trained in the acute management of severe burns.

There are several indications that not all patients with severe burn injuries are timely (or at all) referred to burn care centres. Firstly, among the patients interviewed (and de facto treated in a burn care centre) several reported wrong initial assessments and (too) late referrals to the burn care centre. In addition, the analysis of administrative databases indicates that a considerable proportion of patients with severe burn injuries are not treated in a burn care centre.

All hospitals that admit emergency patients should use a straightforward uniform triage tool (an operational tool based on clear – and thus adapted – legal admission criteria). This triage would allow the immediate referral of patients with severe burn injuries to a burn care centre. During the development of such a referral guide special attention should go to children (especially the very young ones) since they are a large and vulnerable group for which special competencies are required.

The recently developed British NHS 'National Burn Care referral Guidance' can be a source of inspiration in this respect.¹⁶ It proposes a triage procedure based on TBSA, depth site, mechanism (aetiology) of the burn and some other factors that may impact the severity and complexity of the burn. In the guidance there are thresholds listed as 'refer' (i.e. it is recommended that the patient is referred to the particular level of specialized burn services) or 'discuss' (i.e. in such cases a discussion should take place with a consultant of the burn care centre/unit about a potential referral).

The use of telemedicine (e.g. video-conferencing/sharing photographs) could be explored in an effort to facilitate these consultations.^{17, 18} The same principle could be applied for the less severely burned patients (e.g. general practitioners (GP's) consulting a plastic surgeon in a general hospital). In any case, providing the uniform triage tools is only an essential first step.

A specific course could be developed to train physicians regarding the recognition, assessment, stabilisation and transfer of the severely burned patient. The international applied EMSB-course (Emergency Management of Severe Burns course) could serve as an example.^{19, 20}

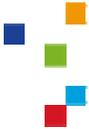
The future college of physicians in burn care could also organize peer-reviewed feedback. A random selection of cases, screened as severe burn injuries but not treated in a burn care centre, could be reviewed in detail by the college of physicians followed by a non-punitive peer reviewed feedback and training.

Recommendation 3

Burn care centres should focus on the care for patients with severe burn injuries.

Non-severe cases should be referred to the appropriate level of care, but they should benefit from short-term specialized advise and/or care in the Burn care centre, on an outpatient or day-care basis, and be referred back afterwards.

When looking at the Belgian data of the Burn care centres, it appears that as many as 44% of the patients being treated in one of the centres do not have a diagnosis of burns, and another 13% have a diagnosis of non-severe burn injuries. Moreover, there is a highly variable and often very short length-of-stay: the median length-of-stay for patients with a registered diagnosis of severe burn injuries is only 4 days (Q1:1 day; Q3: 18 days). For patients suffering burns to hands, feet, genitalia, perineum or major joints (criterion 4) the median length-of-stay is 4 days while this is 40 days for patients admitted under criterion 2, i.e. second and third degree burns larger than 20% TBSA.



Heterogeneity in the legal admission criteria or inappropriate use of high-care beds are possible explanations. Some criteria mean that the patient requires both continuous, close hemodynamic monitoring and highly specialized multidisciplinary burn care. For other criteria (a sub-group of) the patients could only require the latter. Nevertheless, given the absence of accurate national data, more precise figures about the number of patients per criterion in each centre and their activity profile are unavailable.

For the sub-group of patients with non-severe burns, Burn care centres could provide short-term specialized advise and/or care (e.g. outpatient consultations, one-day hospitalizations) and (back-)refer patients to the appropriate level of care (see 4.1.4). The one-day clinic for children already exists in the Military Hospital.²¹

Other interventions

Other interventions to ensure that patients with (severe) burns receive the appropriate level of care are for instance:

- Organization of awareness campaigns targeting emergency care physicians/paramedics and GP's to inform them about the offer of specialized services as well as about the triage tools that should be used to decide about referrals (see Recommendation 2).
- Optimalization of the use of high-care beds (see 4.1.4.).
- Financial incentives such as restricting the payment of specific, more specialised burn treatments, to Burn care centres.

The follow-up of (in-) appropriate referral will require the development and implementation of a specific national burn registration system (see 4.4.3)

4.1.3. *The bridge to aftercare*

The discharge from the Burn care centre is considered as a crucial moment in the care process. Yet, there appears to be a substantial variability between the centres in the way patients are prepared to this step, and there is a lack of elaborate discharge protocols. Other examples of practice variation are:

- The disciplines involved in the process, ranging from the plastic surgeon and care coordinator only to the entire multidisciplinary team;
- The role and responsibility of the care coordinators can be limited to the wound care plan versus span the entire case-management of the post-discharge care plan;
- The most frequently chosen care trajectories: duration, destination after discharge.

The cornerstone of the discharge policy is a well developed patient-centred individual care plan.

Recommendation 4

Burn care centres should develop an elaborate discharge procedure, including an individual patient-centred care plan, accessible to all caregivers involved in the care for this patient.

A clear and uniform role description and quality criteria for care coordinators should be developed together with objective and verifiable measures to evaluate their performance.

The care in post-acute phase is characterized by chronic care needs. This requires a planned and pro-active approach oriented towards goals that have been defined in collaboration with the patient, his/her relatives and the caregivers involved. The ultimate aim of health services for patients with severe burn injuries is to help them to improve their quality of life and the way they can function in society.

The discharge plan is the result of a structured communication and information exchange involving the multidisciplinary team of the Burn care centre, the patient and his/her relatives and the healthcare professionals to which patients are referred.¹⁵



The care coordinator should be the healthcare professional with the global overview, initiating and coordinating the care plan. In some Burn care centres; this person already takes up the role of discharge and/or case-manager. However, the variability in their role and responsibilities necessitates the development of a clear and uniform role description with corresponding quality criteria (e.g. educational level, minimal/maximal caseload) and objective, verifiable measures (e.g. availability of individualized care plan, report of contact with primary care-givers; and up-to-date contact list of skilled primary caregivers) for follow-up.

The external liaison function, developed in the framework of the geriatric care programme²² includes an external liaison service for discharge. This organisational model could be used as an example for burn injuries

Sharing information on the medical history and care plan is vital to ensure that all partners in the care process would take coordinated actions, and that transition between the burn care centre and other care levels does not disrupt the continuity of care along the lines of the individual care plan.

Characteristics of the shared care plan

The care plan needs to rely on the evidence when available (see 4.3.), taking into account the complexity of the problems that the patients and their family face. The goals will be spelled out in terms of quality of life, reintegration and functioning in a long-term perspective.

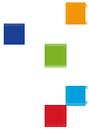
Over and above being a classical medical record for storage of history, findings, results, etc., this electronic, individualized, patient-centred care plan should also¹⁵:

- Include tools for needs assessment (including psychological and social needs), planning and evaluation. The latter should include regular evaluation of the patient's functioning (including daily activities and social life) by means of standardised tools. The Belgian burn care sector should come to a consensus on which of the internationally available instruments to use (e.g. International Classification of Functioning, Disability and Health; ...).²³
- Be shared between professionals, with levels of disclosure and access appropriate for each of them. It should give the patient the right to determine who is entitled to consult/to write in his/her record.

- Reduce the administrative workload of healthcare providers by a.o. avoiding duplicate information input. It could also generate standardised information that allows the patient to benefit from specific services.
- Mandatorily come under electronic format, easily accessible to all relevant parties, but with all required safeguards for the confidentiality of the data.
- Be extensively field-tested in close collaboration with the users.
- Be fully integrated into the framework of eHealth and eCare.²⁴ Softwares used by the different health professionals should be compatible to allow information exchange.

Other suggestions to ease the transition to another institution or to home

- An extensive information kit including a patient leaflet, video materials, contact details of patients organizations adapted to the different target groups (e.g. very young children).
- A common minimal discharge protocol/checklist was supported by many of the interviewees.
- The function of discharge manager needs to be included in the profile description of care coordinators.
- Care coordinators should have access to a formal register to refer to trained and accredited healthcare professionals (see 4.1.4.).
- Inviting primary healthcare providers (e.g. physiotherapists) to the burn care centre to train them prior to discharge, or extensive communication after discharge (e.g. via video-conferencing).
- A gradual discharge process: e.g. patients returning home for only one day, or for the weekend to explore how they manage at home was perceived as helpful, but needs further evaluation, including home visits.
- Pre-discharge home visits by occupational therapists, could be useful to maximise independence. The therapist may provide equipment, adapt the home environment and provide education.²⁵



- Reintegration efforts at school and workplace. Patients with severe burn injuries are out for a long period of time. After hospitalization they need to pick up their former life, but with new body conditions: scars (and the time needed to take care of scars), functional limitations, fear of reactions from the outside world, often withhold them from functioning as before. Going back to work or school demand adapting expectations, both of the patient and of the people around him/her, but this is essential for a good re-integration in society. This can be supported by outreach visits by healthcare professionals from the burn care centre, but also by other means (e.g. video's; training material; education material for the teacher or occupational health staff; programs that aim to actively connect classmates with the burned child during its absence²⁶).

Conditions for implementation

- Healthcare workers should get training to implement a patient-centred, collaborative care plan, and acquire a sound knowledge of the available services (e.g. juridical advice, sources of financial support, reimbursement rules) that might be proposed to the patient.
- Implementation is also conditioned by the availability of effective tools (e.g. standardised instruments; electronic platforms; common guidelines) to support them in this task.
- And, finally, one should not disregard the many innovative local initiatives that emerged bottom-up to ease transition to another care institution or to home. Some of them could be diffused on a large scale.

4.1.4. A range of structures between Burn care centre and home Recommendation 5

Transform a proportion of the high-care beds of burn care centres in less intensive alternatives. The choice for the alternatives and the scale of this transformation should be guided by a standardized measurement of the required capacity via a national burn care registration system.

Burn care centres are high-care facilities staffed and equipped to provide multidisciplinary (often labour-intensive), specialized burn care to the critically ill. As shown above, some centres admit patients with medium care profile as well, or keep patients with (severe) burn injuries in the high-care unit until they can be discharged home.

There is room for optimizing the use of high-care beds by transforming a proportion of them in medium-care beds. Some burn care centres already have medium-care beds which they use to:

- Admit patients with non-severe burns that need advice from a dedicated multidisciplinary team with specific competencies.
- Transfer patients from high care when there is no longer a need for intensive continuous monitoring or ventilation.

Possible scenarios to create an intermediate level of care

- Transforming some of the high-care beds in medium-care beds within the architectonical boundaries of the current Burn care centres. Burn patients are prone to infectious complications, and treating them on the same, well equipped, architectonical ward without mixing them with other types of patients could decrease this risk. In addition, it would prevent the problems of discontinuity of care reported by patients transferred from burn care centres towards general hospital wards. Still, a disaster management plan should foresee the transformation of these medium-care into high-care beds if required.

Concomitantly, an alternative specialized care and advice service should be further developed, such as specific burns day care and outpatient consultations.



- Using general wards, at the same hospital site, as medium-care wards (e.g. pediatric and plastic surgery wards) for patients no longer requiring intensive care. Yet, choosing this option implies the provision of adequate staffing in general wards both in terms of numbers (e.g. for patients with labour-intensive wound care needs) competencies (e.g. specific burn care skills) and disciplines (e.g. physiotherapists, psychologists, occupational therapists). Additional measures to ensure continuity of care should be put in place (e.g. individualized care plan, care pathways covering the entire patient stay).
- Using general wards of the same hospital as well as a limited number of general wards from other hospitals as step-down units with medium-care beds. This option is similar to the previous one but would increase the geographical accessibility in underserved areas. These sites could also be used as hubs of the burn care centres to organize multidisciplinary ambulatory follow-up in an attempt to decrease drop-out, transportation costs and burden. The conditions for implementation are similar to those of the previous option.
- Developing alternatives to the hospital for patients with complex needs. Some patients with a severe burn injury can (temporary) not stay at home, given their physical and / or psychological status. Enhancing the capacity of specialized multidisciplinary ambulatory burn care teams (see 4.1.4.) in combination with an intermediate care facility outside the hospital environment could facilitate earlier discharge, and help to solve transitional situations, at a lower cost than institutionalisation. The need of developing alternatives close to the patient's environment as pointed out in the context of the position paper of chronic care is also relevant in this context.¹⁵ Illustrations are day care centres, respite care, social support at home, service flats, and telematic support.

The choice between these options (or a combination of them) should be guided by data that are currently not available (see 4.4.3). In any case, the options have implications for staffing, payment, regulation, ICT, training, quality assurance processes, etc.

Recommendation 6

Develop additional specialised burn rehabilitation capacity, especially for children.

Patients with severe burn injuries are sometimes referred to rehabilitation wards unable to offer the specialized care they need, surrounded by patients with a completely different profile. This is especially problematic in case of children. Parents stress the importance of a total package of care that provides continuity of care and integrates 'normal life' (like going to school) in the rehabilitation process.

Most consulted stakeholders plead for a small number (one to three) larger rehabilitation centres with a special focus on the assurance of adequate burn care competencies among the available staff (e.g. wound care competencies of nurses working on rehabilitation centres). Others rather favour specialized competence-building in a larger number of existing rehabilitation centres. Anyway, one should keep in mind that **the need for this type of residential rehabilitation will remain relatively low, requiring only small-scale interventions.**

Whatever option is taken, these rehabilitation centres should be an integral part of the burn care networks, with formal agreements regarding clinical and organizational aspects (e.g. staff competencies; exchange of expertise in both directions).

The referral process from burn care centres towards residential care facilities should be based on a patient classification system including aspects such as functional limitations, age, socio-demographic context factors, co-morbidities.²⁷

Recommendation 7

Develop and mobilise burn care competencies in primary care by:

- **The definition of specific burn care competencies and criteria for allied health professionals (i.e. nurses; physiotherapists).**
- **The official recognition of health professionals fulfilling these criteria and by granting them access to (the reimbursement of) specific burn care procedures and services, and, more specifically, by implementing the special nursing title and special nursing competencies in wound care as foreseen in the Royal Decree of 27/09/2006.**
- **The production, publication and maintenance of an inventory of allied health professionals that are eligible for specific reimbursements for the care of patients with severe burn injuries.**
- **Further developing existing post-graduate education programmes for nurses and physiotherapists, in specific burn care competencies.**

In general the follow-up of patients with severe burn injuries is done by the multidisciplinary team at the burn care centre. Patients also (prefer to) receive care at home, by primary care providers (home nurses, physiotherapists).

Still, knowledge regarding burn-related care issues is limited outside the burn care centres, and the lack of a formal list of competent primary care providers, makes it hard for the patient to find a nurse or physiotherapist with the right skills (see scientific report 4.4.4.2.).

Private initiatives such as the Scar Academy (see scientific report 3.3.3.) try to accommodate these training needs but they are vulnerable, as they are not structurally anchored. It would be preferable to integrate such training in the formal education system, e.g. as post-academic courses, to ensure the quality of the programme and the formal recognition of those who graduate. Moreover, they should capitalize on existing models. Effective implementation of the special nursing competencies and titles in

wound care^c, as foreseen in the current legislation, is a logical step in this respect. The curricula should be evaluated and further adapted to warrant sufficient skills in wound care.

The FOD - SPF Public Health should maintain a registry of nurses with special competencies and titles in burn care. Burn care centres could then use this list to more adequately refer their patients. It is suggested to integrate the existing RIZIV - INAMI initiative of 'resource nurses in wound care' in this initiative.²⁸

The same principle can apply to other healthcare professionals, but would require these other professional groups to develop their own professional standards for burn care on the basis of which these curricula can be developed.²⁹

4.2. Supporting the patients and their relatives

Engaging and empowering patients with severe burn injuries and their relatives during the entire care process should be an objective for all involved health professionals. This requires that health professionals are made more sensitive to the role of patients/informal caregivers as partners in the care team and that appropriate skills, intervention programmes and tools are developed.¹⁵ Patient associations can provide highly useful expertise to these programmes by sharing first-hand experiences and perceptions with care providers.

There are several patient and/or charity organizations specifically oriented towards the support (including financial support) of burn victims, and they have more or less similar objectives (see scientific report 3.3.). This has the advantage that their activities are relatively well embedded in the local communities.

^c Verpleegkundige gespecialiseerd in de stomatherapie en in de wondverzorging or Infirmier spécialisé en stomathérapie et soins de plaies/ een bijzondere deskundigheid in de wondverzorging or expertise particulière en soins de plaies (www.health.belgium.be)



The other side of the coin is that there is a certain degree of fragmentation and duplication of efforts, e.g. with respect to patient representation at the level of the decision making bodies, or the set-up of public awareness campaigns. Furthermore, some patients complained about the poor accessibility of their services (e.g. legal support, reimbursement of transport costs) or were even not aware of their existence.

Recommendation 8

The benefits and services of supportive charity organisations should be made more accessible, a.o. by improving their visibility for the patients and the social service office and care coordinators of the Burn care centres and hospitals.

Among the initiatives set up by these organisations are burn camps and cures, in line with the international literature³⁰. They were evaluated quite positively by the consulted experts, stakeholders and patients, and could be further developed (e.g. by giving financial support not only to the patient but also to his/her partner or informal caregiver when required). Other activities that patient organisations could support are for instance, the use of social media to facilitate contacts between peers (see scientific report 4.4.5.).

To improve their visibility and the access to the services and benefits they offer, these organizations should work on a more systematic information of the patients during the initial hospitalization period (e.g. through site visits, patient leaflets), and should also more involve the social service offices and care coordinators of the Burn care centres and hospitals.

4.3. Knowledge development

Recommendation 9

The development and implementation of guidelines for aftercare, adapted to the complexity of the care for patients with severe burn injuries should be supported.

The observed variation in the post-acute care for patients with severe burn injuries both within and across burn care centres is substantial (see scientific report 3.2; 4.3.2.4.; 4.3.5.). The lack of standardization is reinforced by the shortcomings in the current payment system (see 4.4.) contributing to heterogeneity and inequity in the service offer. Indeed, some Burn care centres are able to offer solutions for non-reimbursed services, e.g. thanks to the contribution of charity organizations, while others are not.

A call for the development of guidelines

Most healthcare professionals advocate more standardization of the care process (through guidelines, protocols, care pathways...). Unfortunately, there is a lack of rigorously developed clinical guidelines and methodologically sound clinical studies in this domain of research (see scientific report 5.4.).^{31, 32} However, the sketchy available evidence and the heterogeneity and complexity of patient care needs cannot be a pretext for not developing clinical guidelines, protocols and care pathways. Insofar as evidence-based practice is defined as “the integration of best research evidence with clinical expertise and patient values”,³³ a structured consultation of experts and patient preferences could usefully complement the available scientific literature. Guideline development agencies (such as KCE), in close collaboration with the BABI (or the future college of physicians in burn care) could develop national clinical guidelines for aftercare.

Implementation through care pathways

These guidelines could be further implemented by care pathways (“zorgpaden - itinéraires cliniques”), aimed to standardize practice and to enhance coordination of care “for a well-defined group of patients during a well-defined period”.³⁴ These pathways should be best developed at the level of burn care networks, and should encompass ambulatory follow-up.

4.4. Payment systems and governance

4.4.1. From fee-for-service to a more integrated payment system

The majority of stakeholders and experts underlined the incompatibility between the current payment system and the provision of multidisciplinary aftercare based on patient-defined needs (see scientific report 4.3.9.1.). Delicate issues include the number and duration of physiotherapy sessions; (non-)reimbursement of psychological support; the very restricted reimbursement of occupational therapists; the insufficient compensation of home nursing for lengthy wound care procedures; parallel and overlapping payment mechanisms for mono-and multidisciplinary rehabilitation services²⁷.

These findings are similar to the conclusions for the patients who need chronic care in general and the implications are therefore similar to the recommendations of the position paper on this topic.¹⁵

Recommendation 10

The current fee-for-service payment system should gradually evolve towards a more case-mix-based, bundled payment for the multi-disciplinary aftercare services for patients with severe burn injuries.

Call for new payment systems

New payment models, such as case-mix adjusted bundled payment systems should allow to better tailoring the care to patient needs. Since 'the average burn patient' does not exist (see scientific report 4.3.3.), a limited number of sub-groups should be defined, in accordance with the standardization of clinical care processes (see 4.3.).

Conditions for implementation

New models of payment require thorough preparatory work, including:

- A preliminary analysis of payment mechanisms both internationally (including payment models for integrated care for the chronically ill³⁵) and nationally (e.g. palliative care networks; art 107 for mental healthcare³⁶).
- The development and testing of operational procedures and financial agreements for multidisciplinary collaboration.

- A close follow-up (e.g. monitoring of the quality, efficiency, accessibility, equity, administrative burden) after gradual implementation.¹⁵

4.4.2. Better financial accessibility for the patient

Patients, healthcare professionals and patient organisations in unison stressed the major financial impact of a burn injury on the patient and his/her family. Despite the quite extensive protections offered by the Belgian health insurance system, they do not qualify for some of the benefits granted to chronic patients, and severely burned patients often face financial hardship, especially those already financially weak at the onset (a group reported to be particularly vulnerable for burn injuries).

Specific issues include transportation costs, care products and reconstructive surgery.

Transportation costs

Patients who need a consultation in a burn care or rehabilitation centre several times a week, but are unable to drive themselves are especially vulnerable if they already have financial problems, have a small social network, and little or no informal support. They may face a huge transportation cost, which sometimes leads them to drop out of aftercare. The reimbursement for transport, which is limited to wheelchair-bound patients, is perceived as too restrictive. Some sickness funds or hospitalization insurances offer partial reimbursements, but many patients lack any support.

Wound care products and pressure garments

The long-term use of non-reimbursed medicines and wound care products such as dressings and ointments can be very costly. In addition, these products exist in all price categories but there is no clinical consensus about which products to use: some clinicians prescribe very expensive products while others prescribe cheaper variants for the same indication.

The new reimbursement rules for pressure garments are welcomed, and represent a substantial improvement, especially for children.



Reconstructive surgery

Patients with severe burn injuries have to cope with disfiguration or major changes of their body. This can have a serious impact on their identity, body image, intimate life, self-esteem and self-confidence. For these patients, a number of technical and aesthetical solutions can make the difference. They range from very simple measures, such as make-up, wigs and hairpieces, to very sophisticated reconstructive surgery, hair implantations (incl. eye brows, eye lashes).

Currently, most of these procedures are considered as aesthetical interventions, not reimbursed by the health insurance, while for patients with severe burn injuries they can help to regain their self-image and (normal) social life. Moreover, the criteria for the distinction between reconstructive and aesthetic surgery are not always clear and adapted to severe burn injuries.³⁷

Recommendation 11

To safeguard the accessibility for patients with severe burn injuries to the appropriate healthcare tailored to their needs, it is recommended to:

- **Grant burn patients the same benefits as chronic patients or cancer patients.**
- **Develop information sheets about the prices and indications of wound care products to enhance transparency.**
- **Enlarge the reimbursement conditions for reconstructive surgery for patients with severe burn injuries.**

Similar benefits as other patient categories

Patients with severe burn injuries should be considered as chronic care patients and as such have access to the 'chronic care allowance' (forfait maladies chronique - chronisch zorgforfait) and reimbursement of analgesic medications. Other existing benefits could also be enlarged to patients with severe burn injuries. Examples are the transport fees, currently reimbursed for outpatient chemotherapy/ radiotherapy, for parents of hospitalised children with cancer or for children in rehabilitation centres.³⁸

More transparency in the prices and indications of wound care products

Information sheets could help patients in the purchasing of the cheapest products suited for their needs. They could be developed by patient organisations in collaboration with the physicians/pharmaceutical committees of the different Burn care centres and the College of physicians in burn care, and could; by the same token, help to decrease the reported variability in product prescriptions as well as the contradictory information given to patients (see scientific report 4.4.4.1.).

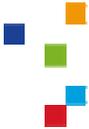
A clear distinction between reconstructive surgery and aesthetic (cosmetic) surgery

In the KCE report 83 on aesthetic surgery injuries,³⁷ we recommended to subdivide the surgical procedures into three lists, by mode of reimbursement: (1) purely reconstructive procedures, always covered by the statutory health insurance; (2) purely aesthetic procedures, that are never reimbursed; (3) a short list of so-called "borderline interventions", only reimbursed after prior approval by the advisory physician of the sickness fund. This approach could perfectly well be adapted to the specific needs of burn patients.

4.4.3. A national burn care registration system

The development, implementation and evaluation of a health policy relies on consistent data of good quality.³⁹ The currently available databases (i.e. the yearly hospital statistics survey and the routinely collected hospitalisation data: the MZG - RHM and AZV - SHA) are insufficiently accurate to get a good estimate of the basic epidemiologic information such as the incidence or prevalence of (severe) burn injuries, let alone more sophisticated information such as long-term follow-up, care profiles, outcome measurement, etc.

Consequently, it is currently not possible to accurately estimate the need for (more) coordinators or rehabilitation services, while these were precisely put forward as potential solution elements by the stakeholders (see scientific report 4.3.9.2.).



The identified shortcomings in the existing databases are plenty, to cite just two striking examples: the ICD-9-CM classification used in the MZG – RHM does not match with the legal admission criteria to burn care centres; the Military Hospital, does not register the MZG – RHM at all.

Several efforts have been undertaken in the past to develop a national burn register, but they got never implemented due to the prevailing distrust of shared data (see scientific report 2.1.).

Recommendation 12

A national registration system for burns should be set up and maintained, providing the basic epidemiologic data needed to guide policy reforms, enhance accountability, and support quality improvement.

One option could be to integrate the ‘burn care registration system’ as a module in the existing Belgian Hospital Discharge dataset (MZG - RHM) and link systematic, exhaustive data submission to the licensing as a Burn care centre. It would require, though, that the Military hospital henceforth also submits its data to the MZG - RHM.

The purpose of a national burn registration system should be to monitor burn injury incidence and causation, and to obtain objective and verifiable data on treatment, outcomes and quality of care.

A step-wise but urgent development is recommended. The first priority is the development of a basic module allowing the calculation of basic statistics about the patients treated in the Burn care centres: demographical data, aetiology, type of injury, information on hospital stay.⁴⁰⁻⁴² In a later stage additional modules could be added allowing the production of more detailed statistics (e.g. drop-outs; long-term outcomes).^{8, 43}

Importance of shared electronic record

The burden of data registration is an often-mentioned barrier experienced by the care providers. Electronic patient records (see 4.1.3) should allow easy data extraction, analysis and export for evaluation purposes. Data export for centralised analysis; benchmarking and feedback should use the eHealth services, and fully make use of the framework offered by the eCare platform.¹⁵ [ENREF 14](#) [ENREF 14](#) [ENREF 14](#) Agreements should be made between burn care centres, the health authorities and the software providers on semantic and data exchange standards, for maximum inter-changeability between the different software's on the market. Only software meeting the agreed requirements should receive the official label needed to comply with the mandatory national burn registration system requirements.



5. CONCLUDING REMARKS

This research project offered the opportunity to patients, healthcare providers, patient organisations and other stakeholders to reflect on the strengths and weaknesses of the current organisation and payment of the services for patients with severe burn injuries.

We identified many well-intended and well-executed bottom-up initiatives that aim to improve the recovery and reintegration of patients with severe burn injuries, and several of these positive local initiatives would benefit from a higher degree of coordination and harmonization to provide an accessible, equitable support to all patients.

When pulling together all solution elements that emerged from the contacts with patients and stakeholders, from our analysis of other, existing initiatives outside the burn care domain, from a scoping review of best practices abroad and from previous KCE-reports, we arrive at 12 recommendations for a more effective organisation of burn aftercare services:

- A first cluster of recommendations focuses on the development of burn care networks (recommendation 1) that bring together all the care that is required at the right time in function of the patient needs and are overlooked by a 'National Network for Burns'. This will require:
 - A better management of patients with severe burn injuries into the care process (recommendation 2).
 - (Back-)referral to the appropriate level of care (recommendation 3), through a streamlined discharge procedure (recommendation 4).

- An optimization in the use of high-care beds by transforming a proportion of this capacity in medium care beds (recommendation 5).
- Expanding the rehabilitation capacity (recommendation 6).
- Strengthening the burn care competencies in the primary care teams (recommendation 7).
- Recommendation 8 targets the support of patients and relatives.
- The next recommendation (9) aims to increase the standardization of the care process on the basis of the best-available evidence by the development of multidisciplinary guidelines.
- The last cluster of recommendations are on a systemic level. Recommendation 10 and 11 are targeted towards improvement in the payments systems to facilitate integrated multidisciplinary aftercare (recommendation 10) and preserve the financial accessibility for patients (recommendation 11); recommendation 12 stresses the need for good data to produce epidemiological statistics about patients with severe burn injuries and their care needs.

The propositions should be considered as a cluster of interdependent solution elements. The process of change is likely to be a lengthy one, and this research represents only one step along that road. The next step would be to transform these recommendations into more concrete actions and reforms with special attention for the (very young) children since they are a large and vulnerable group requiring a particular approach (e.g. entry into the care process; residential rehabilitation capacity; specific clinical guidelines; reimbursement rules such as transport cost).

Table 3 – Main actors involved in the implementation of the recommendations

Recommendations	Universities/ Schools for Higher Education	Professional organizations	Charity organisations	Burn care centres	RIZIV - INAMI	FOD SPF	Federated entities	Minister (law)
1 Regional Burn Care Network				X				
National Network for Burns		X ^d	X ^e		X	X	X	X
2 'National Burn Care Referral Guidance'		X ^{d,f}			X	X		X ^g
Training physicians working in emergency departments	X	X ^{d,f}						
3 Refer non-severe cases to the appropriate level of care, possibly after short-term specialized advise and/or care in the Burn care centre (provide one-day care and short hospitalization alternatives)				X	X	X		
4 Discharge procedure, individual patient-centred care plan				X				
Care coordinator role		X ^d		X	X	X		
5 Transform a proportion of the high-care beds of burn care centres in less intensive alternatives		X ^d		X	X	X		X
6 Specialised burn rehabilitation capacity				X	X	X		
7 Definition of specific burn care competencies and criteria for		X ^{d,h}						

^d BABI (or future college of physicians in burn care)

^e Belgian Burns Foundation

^f College of Physicians for specialized emergency care

^g Adapting the legal admission criteria for burn care centres

^h Technical Council for Physiotherapy; Technical Council for Nursing



Recommendations	Universities/ Schools for Higher Education	Professional organizations	Charity organisations	Burn care centres	RIZIV - INAMI	FOD SPF	- Federated entities	Minister (law)
allied health professionals								
Recognition of health professionals (specifically implementing the special nursing title and special nursing competencies in wound care)						X		X
Inventory of allied health professionals						X		
Further development of existing post-graduate education programmes	X	X ^d					X	
8 Making benefits of supportive organisations more accessible			X	X				
9 Guidelines for aftercare		X ^d				X ⁱ		
10 Integrated payment systems		X ^d			X	X		X
11 Grant burn patients the same benefits as chronic patients or cancer patients.					X			
Information sheets about prices and indications of wound care products.		X ^d	X					
Reimbursement conditions for reconstructive surgery		X ^d			X			
12 Burn care registration system		X ^d		X	X	X ^j		X

ⁱ With support of guideline development agencies such as KCE, CEBAM

^j Also including the Federal Public Service of Defense



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