

June 8, 2017



Report on the 2nd meeting of
The Africa Spinal Cord Injury Network (AFSCIN 2)

Dar es Salaam, Tanzania

March 30–April 1, 2017



ottobock.

livability

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Executive Summary

On March 29th, 2017 representatives from 14 countries gathered in Dar es Salaam, Tanzania for the second conference of the Africa Spinal Cord Injury Network (AFSCIN). The conference (AFSCIN 2) was a multi-disciplinary gathering, involving people living with spinal cord injuries (“consumers”), caregivers, health care providers (e.g., occupational/physiotherapists, nurses, physicians, surgeons, etc.) and researchers.

AFSCIN is affiliated with the International Spinal Cord Society (ISCoS), which supported the conference alongside AFSCIN partners from the Rick Hansen Institute (Canada), Ottobock (South Africa), Livability International (UK), and the Stoke Mandeville National Spinal Charity (UK).

AFSCIN 2 carried forward a vision for spinal cord injury (SCI) first set out at the inaugural meeting of AFSCIN in Botswana in 2015. Objectives for AFSCIN 2 were to:

1. Convene the SCI community to strengthen the AFSCIN
2. Using the outputs from AFSCIN 1, come to consensus on a prioritized action plan with specific goals, milestones, and accountability
3. Identify champions who can provide leadership for the network over the next six months, and initiate implementation of the plan
4. Provide education and training for SCI care providers and consumers.

Participants developed action plans in four theme areas first identified at AFSCIN 1:

- A. Advocacy
- B. Improving Service Delivery
- C. Research
- D. Strengthening AFSCIN: Communication and Coordination.

Each action plan included a dedicated contact person as well as detailed milestones, with the intent that all action plans reach their conclusion in time for AFSCIN 3, to be held in the fall of 2018 in Lusaka, Zambia.

Conference feedback was overwhelmingly positive, with an average of 4.8/5 from 32 responses (for the full feedback report, see Appendix 2). A key mention from the evaluation was the positive energy, networking, and momentum generated by the assembling of such a diverse and talented group of people to plan and prioritize how to improve the lives of people living with spinal cord injury in Africa. In the words of one participant: *“The people were beautiful, and presentations and hospitality were great. However, the best thing was the passion to make changes in SCI management in our various countries.”*

In closing the Conference, the Chair of AFSCIN Ms. Elma Burger spoke of the incredible contributions of participants, the diversity of perspectives, and of her enthusiasm for watching the action plans unfold in the months to come.

For more information, or to get involved in the network, please visit afscin.org.

Introduction

On March 29th, 2017 representatives from 14 countries gathered in Dar es Salaam, Tanzania for the second conference of the Africa Spinal Cord Injury Network (AFSCIN). The conference (AFSCIN 2) was a multi-disciplinary gathering, involving people living with spinal cord injuries (“consumers”), caregivers, health care providers (e.g., occupational/physiotherapists, nurses, physicians, surgeons, etc.) and researchers.

The first meeting of AFSCIN took place in 2015, in Gabarone, Botswana, bringing together individuals and organizations in SCI for the very first time in Africa. Outputs were the sharing of experience and expertise and a vision for spinal cord injury.

AFSCIN 2 carried that vision forward vision – the purpose of AFSCIN 2 was to continue to “establish a network that can be a catalyst for change and a model for effective networking, exchange, collaboration, and advocacy on the African Continent.”

Objectives were to:

5. Convene the SCI community to strengthen the AFSCIN
6. Using the outputs from AFSCIN 1, come to consensus on a prioritized action plan with specific goals, milestones, and accountability
7. Identify champions who can provide leadership for the network over the next six months, and initiate implementation of the plan
8. Provide education and training for SCI care providers and consumers.

The planning and preparation work for AFSCIN 2 was led by the Chair of AFSCIN, Elma Burger, in collaboration with a conference Planning committee consisting of:

Elma Burger, Chair, Rehabilitation Coordinator, Gauteng Province, South Africa

Phalgun Joshi, Managing Director, Program Operations and Support, Rick Hansen Institute, (Canada)

Bylon Kondowe, Consumer, Spinal Injuries Association of Malawi, (Malawi)

Simon Mallya, Occupational Therapist, Kilimanjaro Christian Medical Center, (Tanzania)

Stephen Muldoon, Assistant Director, Livability, ISCoS Education Committee Chair, Asia Spinal Cord Network (ASCON) representative, (Ireland)

Fiona Stephenson, Nurse, Healthcare Capacity Building Consultant, (England)

François Theron, Orthopedic Surgeon, South African Spinal Cord Association (SASCA) representative (South Africa)

Mike Tomlinson, Facilitator (Canada).

About AFSCIN

AFSCIN was formally launched at AFSCIN 1, held in November of 2015, in Gaborone, Botswana. It was envisaged that the network would act as a platform to:

- Share models of best practice from across Africa
- Provide training appropriate to the needs of the African continent
- Promote lesson learning through sharing of successes and failures
- Support the establishment of specialized spinal unit services on the continent
- Facilitate the creation of country-specific spinal cord injury organizations
- Foster research and clinical excellence
- Duplicate good examples of care across the region
- Network with governmental and non-governmental organizations, academic institutions and other service providers
- Link professionals into existing SCI professional networks affiliated with ISCoS.

A key feature of AFSCIN is its focus on working with, and through, people living with and affected by spinal cord injury. It is a core value of the network to include consumer leadership in all aspects of network decision-making.

AFSCIN is closely affiliated with the International Spinal Cord Society (ISCoS); several members of the AFSCIN 2 planning committee sit on the ISCoS Education Committee, including the Chair, Stephen Muldoon.

Since 2015 AFSCIN has grown as a network, and now consists of 175 people from 21 member countries.

AFSCIN 2 Conference Overview¹

The conference was opened by Elma Burger, AFSCIN Chair, who welcomed participants and brought regrets from Dr. Abdallah Possi, former Tanzanian Deputy Minister for policy coordination, parliamentary affairs, employment, and persons with physical disabilities. Ms. Burger also brought regrets from the country representatives of Morocco and Cameroon.

Ms. Burger commented on how wonderful it was to see participants from AFSCIN 1, but also how proud she was to note new faces at the conference. Ms. Burger also gave a special mention to consumer participants, many of whom made long and often difficult journeys to the conference, saying “our consumer colleagues are the lifeblood of AFSCIN – they will carry the network forward and spread it throughout the continent”.

¹ See appendix 1 for the full AFSCIN 2 agenda.

Stephen Muldoon, Chair of the International Spinal Cord Society (ISCoS) Education Committee brought greetings on behalf of ISCoS, AFSCIN's international partner in spinal cord injury. AFSCIN is an affiliated Regional SCI Network of ISCoS. He expressed his enthusiasm for the work to come via the conference agenda.

Phalgun Joshi, Managing Director at the Rick Hansen Institute (RHI), welcomed everyone and brought greetings from Vancouver, Canada. RHI is a supporting partner in AFSCIN, and Dr. Joshi spoke of his hope for tangible Conference outcomes by bringing together a diverse group of participants to focus on improving the lives of those living with SCI and the opportunities of AFSCIN activities to be connected to other SCI networks worldwide.

Faustina Urassa, CEO of the Songambebe Charitable Trust and Project Coordinator with Motivation, provided an inspirational welcome to all. Ms. Urassa spoke of the AFSCIN 1, saying that prior to this gathering, it was thought the light of hope for people living with SCI had been hidden under a table, but that at AFSCIN 1 that light had been revealed to all. Now, at AFSCIN 2, she expressed the aspiration that through this event that light could shine brighter than ever before.

Pre-Conference Survey

In preparation for AFSCIN 2 a survey was sent out to all conference participants. A separate version was also sent to the wider AFSCIN contact list. The purpose of the survey was to identify the respondents' perspectives on successes and challenges with respect to SCI and their expectations for the conference.

Survey responses contributed to development of the conference agenda, and to understand respondents' successes and challenges with respect to SCI. In terms of achievements during the past year, respondents described the development of new infrastructure, dedicated and passionate health care providers, increased advocacy for and awareness of SCI, and peer support interventions.

Challenges included public ignorance about SCI and a lack of awareness, infrastructure, services, human and fiscal resources, supplies and equipment.

Raising awareness was the top action mentioned by survey respondents to address challenges, followed closely by increasing education regarding spinal cord injury.

Part 1: Developing Action Plans

After introductions, Ms. Burger spoke on the state of data for SCI in Africa. A key message from her talk was the need to improve the accuracy, frequency of collection, and publication of African SCI data – an important opportunity for AFSCIN to address in the future.

Participants then moved into the development of action plans for AFSCIN, working in small groups to address four strategic themes:

- A. Advocacy
- B. Improving Service Delivery
- C. Research
- D. Strengthening AFSCIN: Communication and Coordination.

These four themes were identified as key areas of opportunities for and focus of the network at AFSCIN 1, The work of AFSCIN 2 was to use these themes to create specific action plans, including clear milestones and identify supportive champions to move each action forward. Following AFSCIN 2, the network's role will be to coordinate and support, wherever appropriate, the actions described by Conference participants. Put simply, AFSCIN 1 pointed to the desired destination – AFSCIN 2 provided the plan of how to get there.

An overview of the action plans organized by theme follows.

A. Advocacy

As a result of a lack of public awareness and education related to SCI, many incomplete injuries worsen into complete injuries during transportation from the site of injury to hospital. Once at hospital, there is a high incidence of pressure ulcers.

In the community, there is a lack of timely and appropriate services, and a negative attitude towards people living with SCI. Together, these have the potential for early mortality from stress-related ailments. People living with SCI are stigmatized and are at high risk of losing their jobs/income generating activities, becoming socially isolated, becoming completely dependent on others and diminished self-confidence.

The top challenges identified were:

1. Acute management of SCI
2. Community integration, awareness, and accessibility.

Group A Actions

Action	By when	With Whom
A1. Develop (i) education and awareness tools on tissue viability and manual handling (mobile) (ii) education for clinicians in community clinics (in Mauritius)	June – Sept 2017	A. Soopramanien
A2. Expand education efforts on the prevention and management of pressure ulcers in hospitals (in Tanzania)	March 2018	Motivation Tanzania
A3. Design and implement peer group training (in Kenya)	April 2017- Feb 2018	S. Gitau (Motivation)
A4. Participate in peaceful demonstrations for people with disabilities during national and international events when top officials are in attendance. Collaborate with NPO, DPO and local governments.	April 2017- Feb 2018	Kilimanjaro Association for the Spinally Injured (KASI), Shivyawata, S. Mallya, P. Dandi
A5. Engage media in promoting disability issues / educating society about the rights of those living with SCI.	March 2018	KASI, Shivyawata, S. Mallya, P. Dandi
A6. Lobby the government through parliamentary committees of Justice and Constitution and social issues (kamati ya mambo ya jamii ya bunge) to implement Disability Act #9 from 2010 and UNCRPD, 2006.	March 2018	KASI, Shivyawata, S. Mallya, P. Dandi

B. Improving Service Delivery

There is much to be done to improve the current survival rate in many countries and raise the standard for SCI outcomes. If clinical staff are overwhelmed by the care required, satisfaction and empathy are reduced, and the incidence of secondary complications – both medical and psychological – are affected. There is also the fact that people are dying from preventable causes – i.e., pressure ulcers.

Peer support is key in environments where many face economic challenges, and where patients may be discharged without the proper education, training, and materials to manage their care. Many are also at risk of becoming depressed when faced with the realities of their new life.

Some groups focused on actions to be shared across borders (Malawi and Tanzania), while other groups (Madagascar and Tanzania), chose to focus on their own country-specific goals and actions.

The top challenges identified were:

1. Lack of a standardized pathway of care across the health care; lack of standardized rehabilitation process/protocols and infrastructure
2. Human resources, e.g., individuals with the appropriate technical skills, rehabilitation providers, peer group resources, education and staffing, etc.
3. Finances, i.e., of family, extended family, employer if employed, community, church/religious affiliation and charity associations – how to support the best use of funds and lack of wastage.

Group B Actions

Action	Timing	With Whom
B1. Develop an SCI rehab care pathway, connecting information on existing concepts from pre-hospital to life-long maintenance.	<i>First Draft August 2017, final March 2018</i>	S. Muldoon, I. Lövvenmark, K. Sekakela, Francois, Rahm, B. Kondowe
B2. Develop an AFSCIN approved curriculum for peer support training to have patients included as equal members of the rehabilitation team.	<i>March 2018</i>	S. Louis, Jacques Lloyd, F. Urassa, S. Ducharme
B3. Madagascar: Begin planning of rehabilitation project, to be able to move patients into functional rehabilitation immediately after surgery.	<i>April 2017</i>	Madagascar team, hospital management
B4. Madagascar: Negotiate with hospital management for rehab room equipment	<i>Before end of 2017</i>	Madagascar team, hospital management

B5. Madagascar: Organize a 3rd retreat to strengthen links between care providers and SCI patients.	<i>June 2017</i>	Madagascar medical team, patients and their families
B6. Develop more peer support groups. Malawi and Tanzania to educate/share information with new groups.	<i>March 2018</i>	Consumers/care providers in Malawi and Tanzania
B7. Source a caregiver training resource manual (not culturally-specific that could work for all members of AFSCIN. Update as required.	<i>March 2018</i>	M. Skeen, P. Mashaka
B8. Initiate multidisciplinary teamwork in Dar es Salaam (Mwabhili Orthopaedic Institute).	<i>March 2018</i>	E. Mpunga
B9. Initiate institution specific feasibility studies – what is current practice, what is available, and what are the minimum requirements of care.	<i>September 2017</i>	Dr. Brian Sonkwe, AFSCIN Member Countries
B10. Using results of feasibility study, establish SCI teams/equipment where required. Who is going to put pressure on hospital management	<i>AFSCIN 4 (2020)</i>	Hospital administrators

C. Research

Although there are a number of facilities in Africa where research is being conducted, a low number of studies are published. For example, it is estimated that approximately only 10% of all studies undertaken at the Kilimanjaro Christian Medical Centre (KCMC) are being published. Standardized SCI datasets are also lacking across Africa, making it impossible to compare information from different institutions and jurisdictions.

The challenges identified in the Research theme were:

1. Lack of venues for sharing and reviewing research
2. A lack of a standardised data set for Africa.

Group C Actions

Action	Timing	With Whom
C1. Form a research group within AFSCIN on WhatsApp.	<i>March 30th</i>	Action Complete
C2. Develop a standard African core dataset; review with research group; test on 2-3 patients.	<i>June 1st</i>	Research email list Conran Joseph
C3. Develop an AFSCIN web page for research, complete with log-ins, sharing capabilities.	<i>Fall 2017</i>	AFSCIN leadership

D. Strengthening AFSCIN: Communication and Coordination

Sustainability of AFSCIN is an ongoing challenge. For example, funders don't always understand exactly what AFSCIN is or what it does, and without accurate data on SCI and network activities it can be difficult to make the case for additional support. Further to that, without official status as an NGO many companies and foundations are reluctant to provide support to AFSCIN.

The top challenges identified were:

1. Relevant, sustainable, representative governance
2. Communication in different languages, lack of platforms
3. Funding: lack of legal entity, funding strategy, and data to secure funds.

Group D Actions

Action	Timing	With Whom
1. Raise Funds (to sustain AFSCIN for 5 years; includes a full-time administrator).	<i>December 2017</i>	F. Theron (get budget information)
2. Agree on organisational structure. Working group formed to develop a constitution (July 31, 2017); constitution approved by email (March 2018)	<i>March 2018</i>	AFSCIN Executive/E. Burger
3. Develop communication strategy with key messages, right audience and strategy (be on radar of ministry). Create a logic model, get more consumers involved using Facebook, Twitter, webpage, email list etc.	<i>September 1st, 2017</i>	P. Dandi
4. Develop AFSCIN infrastructure, e.g., bank account, NGO status, website administration.	<i>September 2017</i>	AFSCIN Executive

Part 2: Research Presentations

On the second day of the conference, following a brief review and presentation of the small group action plans, the Conference shifted to the presentation of research. The topics are included here for reference purposes – full presentations are available on request from africasci@gmail.com.

Louis, Kondowe:	Spinal Injuries Association of Malawi (SIAM) – progress since AFSCIN 1
Löfvenmark:	Living with TSCI in Botswana local epidemiology and outcomes of TSCI
Lungu:	Treatment of fungal spinal infection in a resource constrained environment
Masaka:	An audit of the prevalence of and factors associated with secondary health conditions in people with traumatic spinal cord injury post discharge from rehabilitation in Botswana
Mashaka:	Manual wheelchair systems to enhance spinal cord injury client mobility
Moshi et al:	Challenges in rehabilitation and prevention of traumatic spinal cord injury incidents in Tanzania rural area
Rashid:	Hospital-based retrospective study: SCI injury profiles and outcomes
Rakotonirainy, Hariharan	SCI in Madagascar- story, achievements, and future plans
Sekakela KM, et al:	Challenges of no acute set up for traumatic SCI patients as presented by a case of fatal fever of unknown origin
Spinalis Namibia:	Rehabilitation unit outcomes; addressing challenges
Soopramanien, Anba:	Challenges of offering neuro-rehabilitation services in Mauritius

Part 3: Clinical Workshops

The afternoon of the second day and final morning of AFSCIN 2 focused on clinical workshops in support of the fourth objective for the Conference, “Provide education and training for SCI care providers and consumers”.

The first set of talks engaged all participants listening as a group to overview sessions, before breaking into specific groups on the final day for more in-depth talks aimed at consumers, nurses, and physicians respectively.

AFSCIN Annual General Meeting

The AFSCIN executive announced the Executive Committee at AFSCIN 2:

Chairperson: Elma Burger

Vice Chair: Salome Gitau

Vice Chair: Sharon Masaka

Treasurer: Francois Theron

Secretary: Bylon Kondowe

The location for AFSCIN 3 was also announced – Lusaka, Zambia. For further details on actions coming out of the AGM, see Theme D: Strengthening AFSCIN.

Conclusion

The conference closed with brief remarks from four people:

Stephen Muldoon, ISCoS Education Committee Chair, thanked all for their commitment and participation, mentioning how much he was looking forward to the next steps coming out of action items developed at the conference.

Elma Burger, AFSCIN Chair, also thanked everyone for their hard work, sharing Stephen’s enthusiasm for what is to come. Elma reminded all that AFSCIN itself is nothing without the contributions and hard work of its members, expressing her hope that everyone would remember the vision and excitement of the Conference when the time came to get down to the hard work of implementing action plans.

Phalgun Joshi, Managing Director, Program Operations and Support, from the Rick Hansen Institute congratulated participants on their heartfelt collaborative approaches to issues and their willingness to be engaged in following through on the plans developed.

Faustina Urassa officially closed the conference, speaking again of the light held up by AFSCIN 1, now continuing to burn more brightly at AFSCIN 2. She urged all present that now was the time to “move forward together” or in Swahili, “tusonge mbele!”

AFSCIN Partners

Rick Hansen Institute

The Rick Hansen Institute is a Canadian-based not-for-profit organization committed to accelerating the translation of discoveries and best practices into improved treatments for people with spinal cord injuries.

<http://www.rickhanseninstitute.org>



ISCoS

The International Spinal Cord Society (ISCoS, formerly IMSoP) promotes the highest standard of care in the practice of spinal cord injury for men, women and children throughout the world. Through its medical and multi-disciplinary team of Professionals ISCoS endeavours to foster education, research and clinical excellence.

<http://www.iscos.org.uk/>



Ottobock

Since its founding in Berlin in 1919, Ottobock has pursued a vision: to improve the mobility of people with disabilities through innovative products. In doing so, the company equates quality with "Quality for life": the quality of life enjoyed by the people who use Ottobock products every day. People at the centre, their individuality and requirements and needs with respect to functionality, quality as well as design form the basis for the company's enduring capability of innovation.

<http://www.ottobock.com/>



Livability

Livability is a national UK disability and community engagement charity, delivering disability services, community projects, education and training resources that promote inclusion and wellbeing.

Livability's international department focuses on:

- i. The development of sustainable and appropriate SCI - rehabilitation services in emerging nations
- ii. the development of regional SCI networks as platforms for learning, exchange, technical capacity support, standard setting and research, and
- iii. (iii) International collaboration.

<https://www.livability.org.uk/>



Stoke Mandeville Spinal Charity

The second world war created a large number of casualties who were sent to Stoke Mandeville to be treated by a very special man, Dr Ludwig Guttmann. Whilst helped them recover he gave them both the confidence and ambition to compete in various sports. Stoke Mandeville became the birthplace of the modern day Paralympic Games and it continues to hold a very special place in the nation's heart.

<http://www.spinalcharity.org/>

Appendix 1: AFSCIN 2 Agenda

March 30-April 1, 2017

Thursday, March 30, 2017

- 9:00 am Part 1: Welcome and Introductions
Elma Burger, Chair, AFSCIN Executive Committee
Stephen Muldoon, Chair, ISCoS Education Committee
Faustina Urassa, CEO, Songambebe Charitable Trust; Project Coordinator, Motivation
Purpose, objectives, agenda, introductions: Mike Tomlinson, Facilitator
- 10:00am Part 2: The state of the data
Elma Burger, Chair, AFSCIN Executive Committee
Overview of the data on Spinal Cord Injury in Africa; Opportunities for AFSCIN
Q&A
- 10:30am Break
- 10:50am Part 3: Developing Action Plans
Reviewing background documents, report on pre-Conference survey, identifying options
- 12:00pm Lunch
- 1:00pm Part 3: Continued
Developing concrete steps, milestones, and responsibilities
- 2:30pm Break
- 2:50pm Part 3: Continued
Reviewing and refining action plans
- 5:00pm End of day
- Evening Beach BBQ (timing and location to follow)

Friday, March 31, 2017

- 9:00am Welcome back, agenda overview
- 9:10am Part 4: Finalizing actions
Reflections from Thursday: taking a second look
- 10:00am Part 5: Abstract Presentations
Note: order of presentations may change
Louis, Kondowe: Spinal Injuries Association of Malawi (SIAM) – progress since AFSCIN 1
Löfvenmark: Living with TSCI in Botswana local epidemiology and outcomes of TSCI
- 10:30am Break
- 10:50am Part 5: Continued

- Lungu: Treatment of fungal spinal infection in a resource constrained environment
- Masaka: An audit of the prevalence of and factors associated with secondary health conditions in people with traumatic spinal cord injury post discharge from rehabilitation in Botswana
- Mashaka: Manual wheelchair systems to enhance spinal cord injury client mobility
- Moshi et al: Challenges in rehabilitation and prevention of traumatic spinal cord injury incidents in Tanzania rural area
- 12:00pm Lunch (AFSCIN Executive Committee Meeting)
- 1:00pm Part 5: Continued
- Rashid: Hospital based retrospective study: SCI injury profiles and outcomes
- Sekakela KM, et al: Challenges of no acute set up for traumatic SCI patients as presented by a case of fatal fever of unknown origin
- Spinalis Namibia: Rehabilitation unit outcomes; addressing challenges
- Sopramanien, Anba: Challenges of offering neuro-rehabilitation services in Mauritius
- 1:45pm Part 6: Topics of Interest: Overview Session
- Plenary session overview topics:
1. Medical management at admission
 2. acute management of bladder and bowel
- 2:30pm Break
- 2:50pm Part 6: Continued
3. Preventing pressure sores
 4. Lung Physiotherapy
 5. Psychiatric/psycho-social needs of the acute patient
- 5:00pm AFSCIN Annual General Meeting
- All are invited to attend
- To be discussed: AFSCIN 3 2018 host site, constitution, financial arrangements, etc.

Saturday, April 1, 2017

- 9:00am Welcome back, agenda overview
- 9:10am Part 7: Workshops on Managing Spinal Cord Injury
- 10:30am Break
- 10:50am Part 7: Continued
- 1:00pm Conference Closing

Appendix 2: AFSCIN 2: Conference Feedback Report

- *Wherever possible, respondents' original words and phrases are used to represent what a number of responses indicated.*
- *When "e.g.," appears after a statement, the points that follow are examples expanding the main point and represent the range of responses provided in that area.*
- *Unless noted otherwise, main-points are presented starting with those with the most support from respondents; sub-points are arranged in alphabetical order.*

1. Overall, how successful was this conference from your perspective?

Response Choice	Number of Reponses	Percent of Total
1 Not Successful	0	0
2	0	0
3	0	0
4	6	18.1%
5 Successful	27	81.8%

N=33

Average: 4.82

2. What did you like the most?

- The presentations and workshops e.g.,
 - The psychological/psychosocial session was an eye-opener
 - The talk on pressure ulcers.
- Networking, e.g.,
 - Meeting professionals from other countries
 - Sharing experiences with other colleagues on how to improve care to SCI survivors
 - The opportunity for clinicians from across Africa to learn from each other.
- Structure and organization e.g.,
 - Lunches were very good
 - Starting the conference with a recap was a good ice breaker.

Single mention comments:

- AFSCIN 2 led to more people understanding the importance and role of peer support
- Keep the challenges of the spinal cord injury patient in mind
- Remember the ideal: reaching out to the community and involving the family in the whole process of caring for the SCI patient.

3. What did you like least?

- Time management e.g.,
 - Group work presentations were too long and instructions weren't followed
 - The conference had too many objectives: governance, presentations, workshops, steering groups etc.
 - The conference was too short: there is enough material to justify having one more day.
- Allocate more time for clinical talks; go into detail rather than provide overviews.
- Facility and accommodations e.g.,
 - Accommodation rooms were not disability friendly
 - Electronic and Wi-Fi issues during presentations
 - Low quality of presentation formats made them difficult to see
 - Meals and lunch with tea were very close to each other, this makes us sleepy
 - Please choose cheaper accommodations for the next event.
- Nothing: everything was successful.
- Presentation topics e.g.,
 - Management of bladder and bowel, and prevention of sores
 - The use of Baclofen in the treatment of spasticity.
- The lack of government representation.

Single mention comments:

- Budget permitting, have an excursion next time to build and strengthen the team.
- Evaluation forms should have the option to evaluate each day. Include catering.
- Have more presentations on access to suitable wheelchairs/other medical supplies or establishing partners to form rehabilitation centers.
- I would have liked the opportunity to discuss ASIA classification with the presenter and other experts to ensure consistency in classification.
- There was a lack of continuation from AFSCIN 1.

Further Comments:

- AFSCIN 2 was a great conference, e.g.,
 - An informative, high caliber event. Future conferences should see Tanzania's AFSCIN 2 as an example. Job well done Africa!
 - Elma was wonderful – she always listened to our needs.
 - Great organization, given that much of it has been achieved on a voluntary basis. Conference structure and facilities were great.

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- Strengthen the AFSCIN network and increase African participation e.g.,
 - Develop a research mentoring seminar, and support research development with an AFSCIN research committee
 - Government needs to get involved to increase our impact
 - There is need to engage other countries so that AFSCIN grows to a point where we ask for donation from funding bodies in a more focused way
 - We need more advocacy to increase conference sponsorship.
- Communicate as early as possible about the next conference so we can get prepared; keep the lines of communication open regarding the network.
- Please send the presentations to conference participants.
- The people were beautiful, and presentations and hospitality were great. However, the best thing was the passion to make changes in SCI management in our various countries.