

International Consensus on Key Concepts and Data Definitions for Mass-gathering Health: Process and Progress

Sheila A. Turriss, RN, BHSc, MSN, PhD;^{1,2} Malinda Steenkamp, B.Nursing, BA(Hons), M.Phil, PhD;³ Adam Lund, BSc, MD, MEd, FRCPC (Emergency);¹ Alison Hutton, RN, BN, MN, PhD;³ Jamie Ranse, RN, FCNA, FCENA, BNurs, GradCertClinEd, GradCertClinEpi, MCritCarNurs, PhD(Cand);⁴ Ron Bowles, EMA II, BEd, MEdTech, PhD;⁵ Katherine Arbuthnott, BA, BMBCh, MRCP, MSc;⁶ Olga Anikeeva, BHealthSci(Hons), PhD;³ Paul Arbon, RN, BSc, DipEd, Grad Dip Health Ed, MEd, PhD³

Department of Emergency Medicine, University of British Columbia (UBC), Vancouver, British Columbia, Canada
School of Nursing, University of Victoria, North Vancouver, British Columbia, Canada
WHO Collaborating Centre on Mass Gatherings and High Consequence/High Visibility Events, Torrens Resilience Institute, Flinders University, Adelaide, South Australia, Australia
Faculty of Health, University of Canberra, Canberra, Australian Capital Territory, Australia
Office of Applied Research & Graduate Studies, Justice Institute of British Columbia, New Westminster, British Columbia, Canada
Department of Social and Environmental Research, London School of Hygiene and Tropical Medicine, London, England, United Kingdom

Correspondence:

Sheila A. Turriss, RN, PhD
Department of Emergency Medicine
University of British Columbia (UBC)
School of Nursing
University of Victoria
6th Floor, 132 West Esplanade
North Vancouver, V7M 1A2 Canada
E-mail: sheila.turriss@ubc.ca

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Abbreviations:

DD: data dictionary
MDS: minimum data set

Abstract

Mass gatherings (MGs) occur worldwide on any given day, yet mass-gathering health (MGH) is a relatively new field of scientific inquiry. As the science underpinning the study of MGH continues to develop, there will be increasing opportunities to improve health and safety of those attending events. The emerging body of MG literature demonstrates considerable variation in the collection and reporting of data. This complicates comparison across settings and limits the value and utility of these reported data. Standardization of data points and/or reporting in relation to events would aid in creating a robust evidence base from which governments, researchers, clinicians, and event planners could benefit. Moving towards international consensus on any topic is a complex undertaking. This report describes a collaborative initiative to develop consensus on key concepts and data definitions for a MGH "Minimum Data Set." This report makes transparent the process undertaken, demonstrates a pragmatic way of managing international collaboration, and proposes a number of steps for progressing international consensus. The process included correspondence through a journal, face-to-face meetings at a conference, then a four-day working meeting; virtual meetings over a two-year period supported by online project management tools; consultation with an international group of MGH researchers via an online Delphi process; and a workshop delivered at the 19th World Congress on Disaster and Emergency Medicine held in Cape Town, South Africa in April 2015. This resulted in an agreement by workshop participants that there is a need for international consensus on key concepts and data definitions.

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Introduction

Mass gatherings (MGs) are events attended by a sufficient number of people to potentially strain the planning and response resources of a community, state, or nation.¹ Mass-gathering events, ranging from local shows to international sporting events, increasingly are common and many involve national and international participation. Terminology and concepts in MG and mass-gathering health (MGH) literature are defined variously and

MG: mass gathering

MGH: mass-gathering health

WADEM: World Associations on Disaster and Emergency Medicine

WCDEM: World Congress on Disaster and Emergency Medicine

WHO: World Health Organization

VIAG: Virtual International Advisory Group

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Timeline	Activity	Output/Topics
Prior to August 2013	Informal communication and collaboration	<ul style="list-style-type: none"> Literature correspondence in <i>Prehospital and Disaster Medicine</i>¹⁸ Agreement on need for MDS initiative
August 2013	Appointment of person (MS) to organize and support process	<ul style="list-style-type: none"> Meeting times, agenda preparation, minutes, document archive, and sharing
September 2013	Ongoing Skype meetings every six weeks	<ul style="list-style-type: none"> Conceptual discussions: Data points Consensus process Online database requirements Research “beyond” the MDS project
December 2013	Face-to-face meeting (Australia)	<ul style="list-style-type: none"> Team meeting Develop shared understandings of aim, objectives Articulate process for developing research framework and MDS data model
2014/2015	Collaborative writing projects	<ul style="list-style-type: none"> Conceptual underpinnings of MDS initiative Population and event models^{16,17} Initial data matrix and conceptualization of variables of interest
	Delphi Process with MG section of WADEM and WHO VIAG	<ul style="list-style-type: none"> Round 1: consensus on key MGH concepts and definitions Round 2: further refine agreed upon concepts and progress consensus on those where consensus was not achieved in Round 1
April 2015	Half-day workshop with members of WHO Collaborating Centers, WHO VIAG on MGs, and WADEM MG Section, as well as interested participants in the 19 th WCDEM in 2015	<ul style="list-style-type: none"> Gain insight on MDS initiative from broad audience of international MG experts attending WCDEM Develop consensus statement supporting initiative and results to date

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Table 1. Process and Timeline for Consensus Project

Abbreviations: MDS, minimum data set; MG, mass gathering; MGH, mass-gathering health; VIAG, Virtual Interdisciplinary Advisory Group; WADEM, World Association for Disaster and Emergency Medicine; WCDEM, World Congress on Disaster and Emergency Medicine; WHO, World Health Organization.

applied inconsistently. The lack of adequate conceptual analysis and theory hinders the development of a common knowledge base and understanding of the MG domain.²

This manuscript reports on an international collaborative project to establish a MGH “Minimum Data Set” (MDS) and foster international agreement on key concepts and data definitions. The initiative described herein emerged from ongoing collaboration between the authors around MG research and came together as a project after Ransie and Hutton published a paper on using a MDS.³ That report focused on the collection of biomedical data but was in line with work by other researchers who had been addressing similar issues.^{4–17}

Developing international consensus on any topic is a complex undertaking. This report makes transparent the process undertaken and demonstrates a pragmatic way of managing international collaboration. The goal of this initiative was to establish international agreement on key concepts and data definitions that will form the basis for a MGH-MDS to serve small, medium, and large-sized events taking place in low, medium, and high-resource settings. The MDS and accompanying data dictionary (DD) were intended to provide a common set of concepts and terminology for event organizers and planners, responder organizations, researchers, public health officials, and governments. The MDS

format will allow collection of consistent public health and acute care data that will inform MG operations and planning, support research, and advance theory and practice related to MGH. The MDS and DD may also inform database and/or software/application developers in constructing data collection tools.

Process of Collaboration

The participants in the MDS initiative developed a series of collaborative strategies to deal with the diversity of backgrounds (ie, nursing, medicine, public health, security, epidemiology, and Emergency Medical Services) and geographic locations (Australia, Canada, and Great Britain). The following sections outline and provide discussion on the process followed in the initiative to date.

Project Infrastructure

The authors of this report formed a working group and established infrastructure to support the initiative. A significant factor in the success of this collaboration process was the appointment of a person who could dedicate time to organize and support the initiative (ie, set up regular virtual meetings, prepare the agenda, take and distribute minutes, as well as share and archive relevant documents).

A second important element was the inclusion of project management and collaborative communication software and practices.

Who are the Stakeholders?
<ul style="list-style-type: none"> • Identification of key stakeholders and opinion leaders in the international MGH community (eg, Red Cross, Federation Association of Football [FIFA], and International Olympic Committee [IOC]). • Identification of end users for the proposed MDS (eg, event producers, operations leads, clinicians, operations leads, and researchers).
What theory informs, or might inform, the creation of a MDS?
<ul style="list-style-type: none"> • An exploration of the perspectives informing research in MGH, in general, and work on the MDS, in particular (eg, public health and disaster medicine). • Risks and hazards analysis for special events. • The need to create both robust conceptual definitions for key concepts such as “mass gathering” and the accompanying categories (eg, sport, arts, or political). • The value of models to describe the populations of interest in the MGH field.
What are the necessary characteristics of a MDS?
<ul style="list-style-type: none"> • Need to build on existing reports to address gaps in current reporting systems vis a vis acuity designations, case mix, and patient presentation rates. • Imperative that the proposed MDS be “lean” (ie, comprehensive enough to be useful, and at the same time spare enough to be practical).
What is essential to the process of building a MDS for use by an international group of researchers and clinicians?
<ul style="list-style-type: none"> • Need for a Delphi process as a way to involve international MGH experts in the process of building agreement on the proposed framework, MDS, and DD.

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Table 2. Summary of Topics Addressed During Face-to-Face Meeting

Abbreviations: DD, data dictionary; MDS, minimum data set; MGH, mass-gathering health.

Basecamp (Chicago, Illinois USA; 2013) is an online, project management tool that permits members of a project team to work in a common space to track messages, files, task lists, and so on. Importantly, internal messaging is routed through regular e-mail, and recorded in a threaded, time-stamped fashion on the Basecamp site, providing a searchable archive for the collaborative process of the team. Because all messages, files, and attachments can be uploaded to the site by simply replying to e-mail threads, the workflow was seamless with team members' usual inbox routines.

Timeline

The process has consisted of several steps. Table 1,¹⁶⁻¹⁸ details the timeline and work completed for the project, thus far.

Process

Following the 2013 World Congress on Disaster and Emergency Medicine (WCDEM) in Manchester, United Kingdom, the working group participated in virtual meetings via Skype (Luxemburg City, Luxemburg; 2013). These meetings established the conceptual framework for the initiative and covered topics such as the purpose, process, and outcomes; initial set of data categories; articulation of a consensus process; development and operation of an online database; promoting and making the database available; and extension of research past the development of the MDS. These meetings were critical in setting up the first face-to-face meeting.

A core discussion involved identifying the conceptual lenses that would inform the initiative and the MDS. As noted above, the working group represented a diverse set of disciplinary backgrounds and operational roles in MG events. The group noted, both through ongoing discussion and reviews of the existing MG literature, that multiple perspectives could inform data points,

collection, and analysis. For example, many have argued that a public health perspective should be an integral part of the planning, implementation, and follow-up of any MG.¹⁹⁻²³ Others have argued that clinical,^{12,13,24} health promotion,^{25,26} and disaster management perspectives equally are essential.²⁷⁻³⁰ The team reached the conclusion that the proposed MGH framework and MDS should be flexible enough to incorporate all of these perspectives.

The team first met face-to-face at a working group meeting in December 2013. The meeting brought new and existing members together to establish a shared understanding of the aim and objectives of the initiative and to explore each other's viewpoints. The pre-arranged agenda focused on further development of a research framework and the development of an MDS data model (Table 2).

Two outcomes emerged from the initial face-to-face meetings: a series of theoretical documents and a Delphi process to engage international MG experts in further developing and refining the MDS concepts. The working group employed a collaborative writing process to draft a document articulating the conceptual underpinnings of the MDS initiative, two publications describing proposed population and event models, and a data matrix detailing initial conceptualization of the variables of interest in the MDS. These documents were distributed as part of the Delphi process.

The Delphi process is an established, systematic, and structured approach to group communication³¹ enabling a group of individuals to deal with complex issues or problems. This method is appropriate when experts are from different fields and not in direct communication, and where the number of experts is too large for face-to-face meetings.³²

The working group employed a “decision” Delphi methodology, attending to anonymity (optional), iteration, controlled feedback,

and group response³³ with a focus on decision making. The process involved two rounds. In the first round, 60 members of the MG section of the World Association for Disaster and Emergency Medicine (WADEM; Madison, Wisconsin USA) and 151 members of World Health Organization (WHO; Geneva, Switzerland) Virtual Interdisciplinary Advisory Group (VIAG) on MGs were given descriptions of key MGH concepts and definitions, and were invited to participate in an online survey. Fifty-one experts expressed interest and 37 (72%) completed the survey. Basic content analysis and descriptive statistics were utilized to identify areas of consensus (defined as 80% or greater agreement with the definition/description). The working group examined and modified the remaining items, which formed the basis for a second round of the Delphi process. Twenty-five of 37 participants (67%) responded in Round 2. A report detailing the Delphi process and its results is currently in review.

Most recently, the working group conducted a half-day workshop open to members of the WHO Collaborating Centers on MGs, the WHO VIAG on MGs, and the WADEM MG Section, as well as other WCDEM delegates ahead of the 19th World Congress on Disaster and Emergency Medicine in Cape Town, South Africa in April, 2015. The aim was to inform delegates of the work that the team has been doing and to invite others to participate in the process, as well as gain insights into the perspectives of a broader range of available experts attending the WCDEM sessions. During this meeting, a consensus

statement was agreed upon, indicating the support of the workshop participants for a MDS.

Discussion and Next Steps

There is a natural pause in the MDS process following WCDEM 2015 and the publication of the consensus statement developed by the international MG community at the workshop. To date, the initiative has led to the formation of a multinational working group that continues to move forward. Two new initiatives are being undertaken. First, the core working group will be expanded to include the leads for existing WHO Collaborating Centers, and interest in the project is being sought, particularly for members from developing countries. As well, a new round of Delphi surveys will be undertaken to refine the proposed data matrix and populate it with relevant data points and reporting items.

Summary

The relatively limited and unstandardized evidence base for MGH has hindered the improvement of health and safety at MG events. The move towards standardization of data points and/or reporting items of interest will strengthen the development of a robust evidence base from which governments, researchers, clinicians, and event planners could benefit. This manuscript details the methodology used to create consensus on the need for a MDS for use in the context of MGs.

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