



CHAPTER HANDBOOK

TABLE OF CONTENTS

CONTENTS	
Introduction	1
10 Steps to Forming a Chapter	2
Frequently Asked Questions	3
Planning your Conversation with your University	4
Current Regional Campaigns	
Equitable Technology Access Framework (ETAF)	6
Clinical Trials Transparency	8
The COVID-19 Mapping Project	10
The Report Card Project	11
The Free the Vaccine Campaign	12
Chapter Tools	
UAEM Branding Guide	15
Movie List	15
Reading List & UAEM Publications	15
Terminology	15
Structure	15
Directory	15

INTRODUCTION

DEAR UAEM MEMBER,

Welcome to the Universities Allied for Essential Medicines (UAEM) North America Chapter Handbook! We hope that you will find this to be a useful resource as you work to advance UAEM's goals in health equity and justice worldwide.

Since the first student-led victory at Yale regarding an HIV/AIDS medicine, UAEM has grown to become a network of over 100 chapters in more than 20 countries, collectively advocating for a world where no one is sick because they are poor, or are poor because they are sick.

As a non-profit organization rooted in a global movement of university students, UAEM aims to:

- (1) promote access to medicines and medical innovations where barriers exist primarily by changing norms and practices around academic patenting and licensing, supported by our own independent research,
- (2) ensure that university medical research meets the needs of people worldwide and actively supports the creation of new needs-based approaches to R&D and
- (3) empower students to respond to the biomedical access and innovation crisis by advocating for the most promising global biomedical R&D system that works for all.

More supplementary resources can be found on our website at www.uaem.org; be sure to check out the Chapter Resources page as well. When you become a member you also have access to our global alumni and faculty network, funding for certain events and trainings and more. Please reach out to us at info@uaem.org or on social media!

IN SOLIDARITY, UAEM CC 2022-2023

10 STEPS TO FORMING A UAEM CHAPTER

Register your chapter on the UAEM website at this link.

4

6

7

8

Not necessary for UAEM membership but it may be helpful to familiarize yourself with your school's policies for starting a student organization. Complete the requisite steps as needed.

Have new chapter members read UAEM's <u>Code of Conduct</u>, then sign up as individual members on the <u>UAEM website</u> so they have access to UAEM resources and the latest updates. (Each chapter organization is the prerogative of each chapter. Feel free to create any officer positions, or a flat hierarchy, that allow you to organize more effectively!)

Distribute this handbook link to chapter members, and email your outreach coordinator with any follow-up questions from your membership.

Pick an ongoing UAEM campaign from the handbook to engage with. Fill out <u>this form</u> to reach out to the campaign's national leads and receive assistance planning campus actions.

Check in regularly with the <u>North American Coordinating Committee (CC)</u> to ask for support and maintain active chapter status! Some moments you might want to check in at include: while planning a campaign or action within a campaign; during recruitment or leadership transition periods; if you receive a response (or no response) from university administrators.

Read up on SMART goals and identify the first action(s) that you will take to get you closer to your defined goal. If you're still getting organized aim to publish your first campus op-ed within 4 months from registration. Remember to reach out if you're struggling.

Stay updated on UAEM North America's broader efforts by signing up for the listserv <u>here</u>, following UAEM on <u>Twitter</u> and <u>Instagram</u>, and subscribing to the <u>podcast</u>.

<u>Table</u> at an activity fair or host a general interest meeting to recruit members. At this stage, you may also find a professor who shares the same values to serve as a faculty mentor.

Raise money for your chapter! If you can't obtain funds from your student government or similar body, email info@uaem.org and ask for advice from <u>UAEM's Fundraising</u>

<u>Committee</u>. Also, join us for our annual #GivingTuesday campaign every December!

UAEM NORTH AMERICA FAQ

WHAT IS THE ACCESS TO MEDICINES MOVEMENT?

UAEM is part of a broad coalition fighting for health equity and justice. This includes working to improve people's ability to get the medicines they need (which may involve pushing for them to be researched in the first place), regardless of where they live or whether they can pay. This is a global movement which comprises both NGOs and grassroots activists, and overlaps significantly with efforts to resist imperialism and neo-colonialism in the Global South.

WHY DOES UAEM FOCUS ON UNIVERSITY ADMINISTRATORS? CAN'T WE MAKE A BIGGER IMPACT BY TALKING TO CONGRESS MEMBERS?

Not necessarily! UAEM's theory of change recognizes that students have immense power to make an impact at their universities (and we have civil rights activists to thank for that lesson). Universities, in turn, have a great deal of power within the pharmaceutical ecosystem. Changing university policy helps us tackle drug pricing upstream, before drugs hit the market, and without going through the gridlocked legislative process. UAEM has unique power in this regard and no one else in the movement does the work we do. Students have influence on their campuses that outsiders do not. And remember universities are increasingly more aligned with corporate interests that their public missions. It is no mean feat to change university policy!

STILL, CAN UAEM MEMBERS ENGAGE WITH LOCAL/NATIONAL/INTERNATIONAL POLITICS?

Absolutely. Most of our campaigns offer opportunities to organize at these levels, leveraging the role of universities in broader political debates. We just keep our engagement strategic; activists don't succeed by spreading themselves thin.

IS UAEM A PRE-MED CLUB?

While we welcome engagement from pre-med students and medical students, UAEM is for everyone who believes health is a human right and cares about health equity. The organization was founded by a mix of students include law students, and our leadership has included those from all sorts of disciplines.

WHAT ARE SMART GOALS?

SMART goals are the gold standard for planning campaigns: they're a) Specific, b) Measurable, c) Achievable, d) Results-based, and e) Time-bound. You should tailor your objectives to make sure they lead you to the measurable change you want to see. Read more here.

WHAT IS POWER MAPPING?

Power mapping is another campaign planning tool you might want to use. You can follow these steps to identify potential targets and allies on campus as you plan your campaign.

HOW SHOULD WE STRUCTURE MEETINGS?

Each chapter has the freedom to structure meetings however you'd like. Consider incorporating strategy sessions (action planning and communicating with university administrators) as well as political education (watching and discussing an access to medicines documentary or playing a <u>radical card game</u>).

WHAT IS ORGANIZING AND WHY DOES IT MATTER?

Community organizing is one of the core tools to rally mass momentum for social transformation. Marshall Ganz defines organizing as "Organizing is leadership that enables people to turn the resources they have into the power they need to make the change they want". Black Lives Matter co-founder Alicia Garza writes, "The mission and purpose of organizing is to build power. Without power, we are unable to change conditions in our communities that hurt us. A movement is successful if it transforms the dynamics and relationships of power." Organizing strategizing with other groups on campus will help you build power for shared goals.

WHAT IS UAEM UP TO IN OTHER REGIONS OF THE WORLD?

UAEM has active campaigns in Europe and Latin America, with emerging regions in Australia and Asia. If you have friends in other parts of the world who might be interested in volunteering with UAEM, you can reach out to the CC to get them connected. They don't have to study medicine or public health, there's a role for everyone!

PLANNING YOUR CONVERSATION WITH YOUR UNIVERSITY

CREDIT TO: DEVIKA SHENOY, SAPNA RAMAPPA, AND MICHELLE HENNESSEY WHOSE WORK ON THE <u>U.S.</u> <u>REPORT CARD ADVOCACY GUIDE</u> WAS ADAPTED TO CREATE THIS DOCUMENT.

Once you and your chapter have established which campaign you want to focus on, you've completed your research and developed a campaign plan, it's likely that direct engagement with your university's administration is a necessary step. If this is the case, we recommend you utilize the University Report Card tool (<u>US version</u>, <u>Canada version</u>) to arm yourself with information specific to your school. This tool will help you to formulate specific "asks' and create buy-in(s) from your university.

FOUR GUIDELINES TO FOLLOW AS YOU PLAN AND PREPARE TO HAVE A CONVERSATION:

Identifying your ask(s): Whenever you want to set up a meeting to speak with a university official, you want to make it worth their while. Often, you will not be able to accomplish all your goals in one single meeting, and if you want to have easy follow-up, you want to make sure they take you seriously at the out front. Simply put, make a good impression that you are serious. With this in mind, ask yourself these three questions:

- 1. What is the problem at my university? Where are they falling short or where could they do better? (Hint: use the Report Card tool to help you here, i.e. *Georgetown University does not commit to open science frameworks that would increase access to COVID-19 related health technologies.*)
- 2. What is the policy change that would enable the university to do better? (Hint: be specific, i.e. *Georgetown University can commit technology to the World Health Organization's COVID-19 Technology Access Pool.*)
- 3. How can the university make this change? What are the steps? (Hint: use UAEM's various reports and tools to identify action steps, i.e. *Ask the university official to commit to a meeting with a representative from the WHO C-TAP and your group with assistance from members of UAEM's coordinating committee.*)

Here's a recent example from our allies at <u>Global Justice</u>, a <u>sample letter</u> to the Chancellor of Vanderbilt from the Free the Vaccine campaign by the UAEM student chapter at UCSD! Ensure that when you leave your meeting, you have a commitment from the university official (big or small, even if it is another meeting). And do not forget, follow-up is key!

Choosing an angle: Before taking action, choose the angle with which you will approach your university. This involves identifying what is most important to your university. Be efficient and focus on one or two items. Common motivations include reputation and competition but be creative here! Below are some examples.

- Reputation: This angle is best to use when your school values its image as a leader in its
 community. Encourage your university to commit to more equitable practices by saying that it
 will help them improve their image.
- Competition: This angle is best to use when your university values its image as being superior to
 its rival universities. List the accomplishments of rival universities who perhaps outperformed
 your institution in the Report Card section relevant to your ask. Identify what that university
 does that yours does not.

Selecting your contact point: To obtain buy-in you should identify the office in your university that has the most direct authority in making this happen. Contacts can include, but are not limited to:

- Office of the President
- University Technology Transfer/Research Licensing Offices
- Offices of Research and Innovation/Administration
- Global Health Departments/Institutes
- Deans of graduate programs in Public Health, Law, Medicine, Nursing
- University hospital administration and faculty members

What if this process does not work? If your university does not respond to the above, quickly identify faculty and student allies that will join you in applying pressure on your university. In addition, you can use social media to gain support on your campus, finding as many allies as possible. There is always strength in numbers.

CURRENT REGIONAL CAMPAIGNS EQUITABLE TECHNOLOGY ACCESS FRAMEWORK 2020

WWW.UAEM.ORG/ETAF

Every university-developed technology with potential for further development into a drug, vaccine, or medical diagnostic should be licensed with a concrete and transparent strategy to make affordable versions available in resource-limited countries for medical care. To help turn this into a reality UAEM published its Global Access Licensing Framework in 2010 which consisted of 6 principles for universities to adhere to.

However, technology transfer at universities does not just involve direct licensing of a patented innovation to a pharmaceutical company and a more extensive framework covering a wider range of technology transfer modalities was needed. Consequently, UAEM has developed the Equitable Technology Access Framework (ETAF) as a step-up from our previous SRL policy work.

ETAF is a policy framework to support universities in improving the access and affordability aspects of their current technology transfer processes. It helps universities lay out strategies so that when transfers happen, the university can retain as much oversight as possible over what happens with the end products of its initial research findings.

The goals of ETAF are to 1) improve equitable access, (2) promote further development of health technologies, and (3) strengthen the transparency of health technology transfer.

General Principles of Global Access Technology Transfer

As publicly funded research institutions (PFRIs), universities' main priority with the use of research is to maximize return on public investment by promoting the accessibility and affordability of health technologies. For this reason, it is important for the PFRI to hold intellectual property (IP) rights to initial research in order to maximize influence over the end health product. Any transfer or rights to a third party should attach conditions to promote access and affordability and hold these conditions to be applicable to future technologies created. If a third party does not agree to act in accordance to the general principles of global access the PFRI should have the authority to step in and revoke the agreement.

Modalities of Technology Transfer

When outlining the mechanisms of the technology transfer, the rights of the university to hold authority over their research should be prioritized. The university should only transfer their research to third parties that have agreed to produce their product at a marginal cost to low- and middle-income countries during the period of IP protection on the health product. In addition, universities and third parties should ensure transparency by disclosing all relationships/contracts pertaining to the development of health technologies.

Arrangements of Technology Transfer are as follows:

	Licensing	 When a PFRI grants exclusive or non-exclusive rights for a third party to use their research
	Commissioned Research	 When a third party commissions a PFRI to do research on a specific issue
	Product Development Partnerships	When a PFRI will collaborate with other institutions to develop reserarch into a product
	Spin Off Companies	 When a PFRI will create its own company in order to develop research into a product
		·

Mechanisms for Accountability

Regardless of the policy the university adopts from ETAF, mechanisms of accountability are necessary to ensure that universities are adhering to their commitments. Without such measures included in the policy's language to enforce the university to abide by those guidelines, the practice of such principles is insignificant.

Examples of accountability measures include (but are not limited to):

- Publishing full contracts pertaining to health technology licensing on the universities' website
- The university releasing an annual, publicly available, annual report detailing the universities technology transfer pertaining to health technology
- Establishing a research ethics committee with faculty members and students to oversee the technology transfer process of the university
- Outlining potential mechanisms of responsibility and assessment if the university is not upholding their pledge to equitable technology transfer

CLINICAL TRIALS TRANSPARENCY CAMPAIGN

WWW.ALTREROUTE.COM/CLINICALTRIALS/

Overview

- Clinical trial transparency is key to accelerating medical progress, ensuring drug safety and efficacy, and improving access to essential medicines.
- Universities undertake a large portion of all clinical research done in the United States, and it is becoming increasingly important for each university to follow the principle of transparency.
- At the very least, universities must abide by the FDA Amendments Act of 2007 (FDAAA), which legally mandates institutions to report results from a subset of clinical trials within one year of the study's completion.
- UAEM chapters should aim to increase clinical trial transparency at their universities.
- UAEM has released a 2021 and 2019 <u>report and microsite</u>, intended as tools for chapters to use as they raise awareness and put pressure on university leadership.
- As shown in the 2021 <u>report</u>, UAEM's student advocacy has led to a 23% decrease in unreported trials, as well as increases in institutions with 100% reporting rates. 36 out of 40 institutions also had reporting rates above 80% in 2021 as compared to 16 out of 40 schools in 2019.
 - However, this report is only a snapshot of 40 top research universities. There are many more schools in and beyond this report that are yet to achieve 100% reporting rates, and UAEM student advocacy is key at these schools.

Why is transparency important?

- Clinical trial data is crucial for informing researchers, regulators, physicians, patients and the public of the safety and efficacy of treatments and other therapies as they are transitioned from research labs into patient care.
- Of the \$41.7 billion invested annually by the NIH, over one third of that funding goes towards clinical research. Notably, publicly-funded research institutions, including universities, conduct the majority of clinical trials in the US.
- Such information can provide insight into whether licensed and approved drugs, vaccines, and medical devices truly work as well as initially predicted, and in which patient groups they do.
- While some clinical research outcomes may be published, the data is carefully curated.
 Prominent academic journals seldom publish results of studies that have yielded negative or inconclusive results.

- Amidst the COVID-19 pandemic, clinical trial transparency can influence the way future research is conducted; for instance, by informing critical decisions around study design, patient recruitment, risk assessment, and funding.
- As our understanding of COVID rapidly evolves, transparency allows providers to make better-informed decisions about patient care to protect communities that have been disproportionately impacted, such as low-income individuals, the elderly, and people of color.

Clinical trials transparency is also critical to ensuring that research represents a diverse patient population, especially important as providers make decisions regarding which treatments to use for different patients.

What are universities responsible for?

- Clinical trial sponsors, including universities, pharmaceutical and medical device companies, and other types of organizations, are required by federal law to report basic results from many interventional clinical trials pursuant to the FDA Amendments Act of 2007 (FDAAA).
- This legislation mandates that clinical trial sponsors input trial results into the ClinicalTrials.gov database, including null and negative results.
- Universities must report trial results within one year of the study's completion.
- Although clinical trial results reporting is mandated by US law, the FDA has failed to create a system to check and enforce this mandate to ensure complete reporting.

Research institutions that are not compliant with this law are subject to FDA-issued fines of \$10,000 for every late day. However, these fines are rarely imposed by the FDA, making student advocacy critical.

How to get started at your university?

Refer to the <u>UAEM Transparency Advocacy Guide for Chapters</u> for more information.

Analyze your university

- Is your university included in UAEM's transparency report?
- If you search your university on the <u>AllTrials Trial Tracker</u>, do you see any overdue results?
- Are there existing protocols for researchers to submit trial results? (Your university may have an Office of Clinical Research where you can find this information).

Determine your Goal

- Do you know how your university reports clinical trial data? Refer to the <u>2020 US Report Card/2017 Canadian Report Card</u> for more information.
- Who are your allies (professors, student organizations, etc.)?
- How can you involve your university (op-eds, campus actions, social media)?
- How can you raise awareness about this issue on campus?

- 3
- Make your Ask: Meet with University Leadership
 - Can you set up a meeting with your office of clinical research?
- What are your specific asks?
- How can you communicate the importance and urgency of this issue?
- How can you contextualize these goals within the university mission?

Follow-up: Keep up the Persistence

- What are clear, actionable steps that your leadership has agreed to take?
- How can you develop a realistic timeline to keep them accountable?
- How can you continue to use campus actions to sustain the pressure?
- Don't forget to share and celebrate your wins, too!

THE COVID-19 MAPPING PROJECT

PUBLICMEDS4COVID.ORG

What is the COVID-19 Mapping Project?

- The COVID Mapping Project is an advocacy tool developed in collaboration with UAEM students all across the globe.
- It tracks publicly funded COVID-19 diagnostic, therapeutic, and vaccine research projects at university institutions in sixteen countries across North America, Europe, Australasia and East Asia up to December 2020.

Purpose of the project

- It highlights the significant role public funding has
 played in the research and development of COVID-19
 vaccines, therapeutics, and diagnostics to hold
 universities and publicly funded institutions
 accountable.
- Public funding is crucial in the development of lifesaving medical discoveries, and the magnitude of public funding should be reflected in an affordable and accessible price for these discoveries.

Key findings

• Pharmaceutical corporations ModernaTX, Inc., AstraZeneca, Sanofi Pasteur/GlaxoSmithKline, and Pfizer Inc. have received the most public funding for COVID-19 R&D, with a total of over \$8 billion USD since December 2020. Despite this massive investment, no conditions to ensure the fruits of these public funds such as the COVID vaccine remain equitably accessible and affordable to the public. In fact, Moderna, AstraZeneca, and Pfizer are <u>raising their vaccine prices</u>, and Pfizer is expected to make \$15 billion in profit from the vaccine in 2021.

Fun fact

Our COVID Mapping
Project was included
in <u>The world Health</u>
Organization (wHO)
Global Observatory on
Health R&D in 2021!

- See our executive summary for further key stats (<u>linked</u> on the website)
- Also check out our white paper for details on the methodology and region-specific findings (<u>linked</u> on the mapping website)

How can my chapter use this tool?

- Visit the <u>Mapping website</u> to see how much funding your university/region/country has received for COVID-19 research.
- Approach your university's technology transfer office (TTO) to discuss equitable licensing and/or supporting the Open Covid Pledge.
- Raise awareness at your university campus!

Any future plans for the COVID Mapping Project?

- We are open to student volunteers to help update our data. Contact: info@uaem.org
- If you have suggestions about a particular COVID drug to include in the database, we are open to feedback and starting a working group for this.

THE UNIVERSITY REPORT CARD: GLOBAL EQUITY IN BIOMEDICAL RESEARCH

UNITED STATES REPORT CARD CANADIAN REPORT CARD

What is UAEM's Report Card?

- UAEM's University Report Card is a tool that evaluates 60 top American research universities' contributions to research into neglected global health needs and access to medical treatments worldwide.
- The most recent Report Card assigns grades to universities using universityreported data and publicly available data in the following five categories: Access, Innovation, Empowerment, Transparency, and COVID-19 Response.

Purpose & Significance

- The Report Card emphasizes the importance of universities' decisions on global access to medicines and global health equity.
- Namely, this tool puts pressure on universities by giving a grade to them, thus comparing them to other top research institutions while highlighting each school's specific strengths and weaknesses.

Key findings

- Only 22% of universities have committed to specific global access licensing strategies.
- 15% of universities devoted no research funding to global health research; most devote 1-5%.

- 50% of the universities have made NO commitments to equitable COVID-19 biomedical licensing practices.
- For more information about our findings, go check out our white paper!

How can my chapter use this tool?

- Check out your university's grade on the 2020 Report Card! If your university has a grade, you can see the scoring details to understand your school's strong and weak areas in promoting global equity in research.
- If your university does not have a grade, no worries you can still use this tool to pressure your university! Our detailed methodology provides more information on the data we used to determine university's scores. Though we do not recommend giving universities a grade if they have not been evaluated in our Report Card, you can use the methodology to pinpoint how to find specific information about your university's research priorities, policies, and performance. Then, you can use those tools to make a targeted ask towards your university's technology transfer office (TTO)!
 - For example, if your school has poor performance on 'Access', talk to your TTO
 about their licensing decisions. If your school has a poor performance on
 'Empowerment', talk to their global health department about establishing more
 opportunities for students!
- To raise awareness about the Report Card at universities, some chapters have done the following:
 - The UAEM chapter at Case Western made a cake with CWRU's grade and presented it to their TTO!
 - The UAEM chapter at UCLA created a banner with UCLA's grade and hung it up in UCLA's busiest walking path on campus!
- To learn about more strategies for using this tool to pressure universities, go check out our Advocacy Guide!

THE FREE THE VACCINE FOR COVID-19 CAMPAIGN

WWW.FREETHEVACCINE.ORG

What is the campaign?

This campaign is a collaboration between UAEM and the Center for Artistic Activism. The goal of the campaign is to ensure that COVID-19 diagnostic tools, treatments, and vaccines must be sustainably priced, available to all and free at the point-of-delivery.

How does it work?



The campaign has run for 4 active seasons, beginning in March 2020 and continues to meet weekly in 2022. It uses a blend of access to medicines objectives and artistic activism methods to achieve its goals. Its hashtag #FreeTheVaccine has been used to rally comrades for the fight for global equity in access to meds all around the world. Each season has had a slightly different structure and focus. We have focused on universities and their tech transfer offices, in addition to public institutions such as the NIH, as well as private bodies like Moderna and other pharmaceutical companies.

University-Specific Information

- When targeting universities we tried to get them to sign the Open COVID Pledge,
 which states that because
- Immediate action is required to halt the COVID-19 Pandemic and treat those it has affected. It is a practical and moral imperative that every tool we have at our disposal be applied to develop and deploy technologies on a massive scale without impediment.
- We therefore pledge to make our intellectual property available free of charge for use in ending the COVID-19 pandemic and minimizing the impact of the disease.
- We will implement this pledge through a license that details the terms and conditions under which our intellectual property is made available.

Example action: we targeted the head of the technology transfer office at McGill University by making a video tailored to his interests: WATCH

In advocating to your university, creative activism methods can make a big impact. Instead of sending a simple email try staging a creative demonstration on campus or creating something tailored to someone's particular interests.

Major Wins

One of the biggest successes of season 3 was the rally for vaccine equity on May 5th, 2021, on the Mall in Washington, DC. Activists gathered with costumes and signs, to demand that Biden 'free the vaccine'. The day of that DC rally, Biden's administration took the unprecedented step of agreeing to support negotiations for the TRIPs waiver, and major outlets used images of our rally to share the news, including the New York Times, Washington Post, and The Guardian.



Check out a variety of creative actions for inspiration and to learn what worked and what didn't!

https://freethevaccine.org/exhibit/

<u>Lessons Learned</u> from Free the Vaccine for COVID-19 to apply to your campaigning!

More on artistic activism: https://freethevaccine.org/exhibit/strategies/

MORE INFORMATION

CLICK ON THE UNDERLINED LINKS!

UAEM's 6 year International Strategic Plan Find some
helpful UAEM
and UAEMrelated
<u>Terminology</u> and
Structure

Need some
evidence to back
up your
arguments check here
UAEM Evidence

Want to remain consistent with <u>UAEM branding?</u> Look no further!

Looking for UAEM photos? Try here on Flickr and here!

Check out a list of movies to show at your meetings!

Curious about Alternative R&D?
Learn more from <u>UAEM's</u>
<u>AltReRoute & Report</u> (referenced in the UN High Level Panel on Access to Medicines)